ACTION DUCHENNE LIMITED

England & Wales · Charity number 1101971

Details

Other names	PARENT PROJECT UK LIMITED
Status	Registered
Legal form	Charitable company
Company number	04899036
Registered	2004-02-09
Register	View on the Charity Commission register

Contact

Address	Godfrey Wilson Ltd 5th Floor Mariner House 62 Prince Street Bristol BS1 4QD
Phone	07535 498 506
Email	info@actionduchenne.org
Website	www.actionduchenne.org

Activities

Objects: THE RELIEF OF PERSONS WITH DUCHENNES AND BECKER MUSCULAR DYSTROPHY THROUGH SUCH MEANS AS ARE CHARITABLE BY LAW.

Activities: Action Duchenne campaigns and supports research for a cure for Duchenne and Becker Muscular Dystrophy. Duchenne is a severe and progressive muscle wasting disease that leaves young people paralysed and facing early death by late teens. The Charity has launched a Registry for Duchenne patients to help to progress Clinical trials.

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Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£590,523	£673,765	£452,848	12
2024-03-31	£612,379	£642,358	£521,436	10
2023-03-31	£711,864	£580,845	£551,415	9
2022-03-31	£562,186	£359,863	£420,396	8
2021-03-31	£494,338	£367,861	-	-

Trustees

Name	Role	Appointed
Anna Mabile		2024-06-25
Dr Victoria Pleydell		2024-06-25
Emma Rose Simmonds		2024-02-08
Greg Hill		2024-06-25
Marion Main		2025-02-14

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ACTION DUCHENNE LIMITED

England & Wales - Charity number 1101971

Accounts

Company no. 04899036
Charity no. (England & Wales) 1101971
Charity no. (Scotland) SC043852

Action Duchenne Limited

Report and Audited Financial Statements

31 March 2025

Action Duchenne Limited

Reference and administrative details

For the year ended 31 March 2025

Company number	04899036
Charity number	1101971 and SC043852
Registered office and operational address	5th Floor, Mariner House 62 Prince Street Bristol BS1 4QD
Trustees	Trustees, who are also directors under company law, who served during the year and up to the date of this report were as follows:

Roger Cockerton (Treasurer)	Resigned 1 October 2025
Gary Fegan	Resigned 14 January 2025
Greg Hill	Appointed 25 June 2024
Anna Mabile	Appointed 25 June 2024
Marion Main	Appointed 14 February 2025
Dr Victoria Pleydell	Appointed 25 June 2024
Mark Silverman	Resigned 31 January 2025
Emma Simmonds	

Chief executive officer	Florence Boulton	Until 24 May 2025
	Katie Endacott - Interim	From 10 March 2025

Bankers	Barclays Bank UK PLC 77 North Street Keighley BD21 3SA	The Co-Operative Bank PO Box 250 Skelmersdale N3 6WT

Auditors	Godfrey Wilson Limited Chartered accountants and statutory auditors 5th Floor Mariner House 62 Prince Street Bristol BS1 4QD

Action Duchenne Limited

Report of the trustees

For the year ended 31 March 2025

The trustees present their report along with the financial statements of the charity for the year ended 31 March 2025.

Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with current statutory requirements, the Memorandum and Articles of Association and the Statement of Recommended Practice - Accounting and Reporting by Charities (effective from January 2019).

Objectives and aims

Action Duchenne exists to support, empower and equip every DMD community in their journey from diagnosis and beyond. In 2024-25 we did this through our All Through Support programme, and our annual conference, which is a big element of our activity. Read on to hear more about how our activities have fed in to this purpose and objective in 2024-25.

Achievements and impact this year

Throughout 2024-25, we advocated for all families living with Duchenne in translating complex science language into practical terms and proactively journeyed alongside 250 families. While we provide much of our support online and over the phone, we also came to schools and homes to support meetings with Local Authorities and Social Services, and we took young people to residentials and activity days. As has become a tradition, we also brought together families, researchers, clinicians and experts for our international conference.

Action Duchenne is brilliant at providing a wider perspective on Duchenne. The research is so important. But helping families understand the condition, providing a friendly and sympathetic ear, and helping them to access care and assistance is vital for so many on a day-to-day basis. This is where Action Duchenne stands out.



With thanks to Albert Gubay Foundation and the National Lottery Community Fund, we have continued our core programme of work:

- **Working with newly diagnosed families**
  When families receive the diagnosis that their child has Duchenne Muscular Dystrophy, we are there to support them and to help them understand what this means. This year we have had over **30 conversations** with families who are going through this. We know that each week, on average two families are diagnosed with Duchenne, and this we want to be there for every family. Our Outreach Officer is working hard to spread the word and be present at clinics when these diagnoses are made.
- **Helping families make informed decisions**
  Families have information thrown at them when they get their diagnosis, and they need space to process this and understand the full implications of the decisions they're making.
- **Supporting families**
  While we provide the 1:1 support, we also recognise the value of peer support, and we connect families up through a variety of support groups such as Dads Against Duchenne, Mum's Group and Grandparents Together with **64 joining these groups this year**.
- **Transition To adulthood,** with funding from Pfizer Ltd and Sarepta Therapeutics, has continued to develop with regular online meetings, mentoring opportunities and residentials. **There have been over 85 touch points with our young people and their families**. We have also extended this from our 14+ age range, recognising that the transition from Primary to Secondary education is also a challenge for young people. We held a day out together ahead of a Dinner Dance, kindly organised by Ruth Taylor, which celebrated these young people and all that they are achieving.
- **End of Life and bereavement** As is the very nature of Duchenne Muscular Dystrophy, each year we also support families who are going through end-of-life care and facing challenges of bereavement. For many, they face anticipatory grief throughout their life, and the end of life is a large chapter where support from those who understand Duchenne is incredibly valued. We have worked with hospices to provide specialist support, and will continue to do so moving forward.





Our international conference continued to be a highlight of the year, with **over 360 families, clinicians, researchers and industry leaders coming together for two days**. As we continue to listen to what our families want and need, we introduced a space for parents and grandparents to come together and take time out while their children were entertained for 2024. The conference provides an opportunity for families to come together in person, and to find others in similar situations, regardless of geography.

Thanks so much for having us at the conference this weekend: it was especially good for me and my younger son to hear from Pathfinders and Yes I Can about opportunities and advice for a range of things from travel to going to university, clearly explained by panel members with lived experience.

My older son has Duchenne and is himself at university and I thought the advice given about that was accurate and to the point, especially as explained by the eloquent Jack Bosanquet.

It made me feel like more is possible, with planning and a mixture of optimism and pragmatism…We always feel at home when surrounded by people who 'get it'.

Further to this, we developed our work specifically in Scotland, having secured funding from The National Lottery Community Fund and The Hugh Fraser Foundation. We have been planning our first activity day and talking with organisations to establish collaboration opportunities.





Acknowledgements

While as an organisation we achieve so much, it is not without the support of many others. Action Duchenne would be nothing without our staff, who have worked tirelessly throughout a year of change. Thank you for all you do alongside the wonderful community we support.

Our Trustees and Patrons who continue to govern and work alongside our leadership team, thank you. Thank you for keeping an objective eye on the organisation.

To our funders and each and every one of our supporters, you enable us to continue providing support to families when they need it most.

Those who give their time, for free, allows us to achieve so much more. Your support at our international conference and events means our reach is greater and ultimately more families benefit from the support of Action Duchenne.

Looking ahead

As we plan for 2026 and beyond, we have secured further funding from the National Lottery for the next three years of core activity. We will be growing our support team to increase our depth and reach, and increase our collaboration with other organisations supporting those with Duchenne to unite our various expertise and provide the best possible support for our communities.

In 2025-26, we have developed new values, which we will be building out from with our new strategy, and clarifying our purpose, ensuring Duchenne Muscular Dystrophy communities remain at the centre of what we do.

References 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 Fifth Floor, Mariner House, 62 Prince Street, Bristol BS1 4QD.

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:

Gary Fegan	(Chair, resigned 31 January 2025)
Victoria Pleydell	(Chair from 1 February, appointed as Trustee 25 June 2024)
Roger Cockerton	(Treasurer)
Mark Silverman	(resigned 31 January 2025)
Greg Hill	(appointed 25 June 2024)
Anna Mabile	(appointed 25 June 2024)
Marion Main	(appointed 14 February 2025)
Emma Simmonds	

We were delighted to welcome new Trustees, who have been 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 Board would also like to thank all Patrons, staff and volunteers past and present, who have given their time and energy to Action Duchenne.

Introduction

We, the Trustees of Action Duchenne, are pleased to present our report for the year ending 31 March 2025. This past year has seen continued progress in our core work, with development of our governance. Our key priorities are to ensure that our governance and operations are well-aligned with our mission to support, empower and equip every Duchenne Muscular Dystrophy community in their journey from diagnosis and beyond.

Governance and leadership

Action Duchenne is governed by a Board of Trustees, who make sure the charity follows its legal, regulatory, and ethical obligations. Throughout 2024/25, the Trustees held regular meetings to oversee the charity's work, monitor progress, and approve key plans, resulting in a review of governance and increase in meeting regularity to ensure the Charity is compliant.

This year, we were delighted to welcome four new Trustees - Anna Mabile, Greg Hill, Dr. Victoria Pleydell and Marion Main - who bring valuable experience in finance, organisational development, children and healthcare. Their expertise strengthens and refreshes our leadership team as we look to develop our strategy for 2026 and beyond.

We are looking to increase the diversity of the Board, including more Trustees without direct lived experience of Duchenne Muscular Dystrophy, to provide objective support and oversight of the organisation.

Strategic oversight and long-term planning

About us

Action Duchenne continues to exist to support, empower and uplift Duchenne Muscular Dystrophy communities, from diagnosis and beyond. This year, we have also developed values by which we stand. These values are at the core of our work and should be clear in each and every interaction and activity with us:

Supportive, empathetic, respectful, community focused and inclusive.

Financial review

In 2024/25, Action Duchenne had a net loss of £225,304 for the year ending 31 March 2025. This includes a net loss on our investment with PEP-GEN of £142,062. Income from the year totalled £590,523, including donations and income from our conference as our single biggest family event. In 2024-25, we allocated 20.7% of our support and governance costs to fundraising, and 79.3% to charitable activities.

Income and expenditure from 2023-24 has been reclassified to reflect the requirements of the Charities SORP (FRS 102) and to be comparable with 2024-25, having changed auditors. The restatements reflect reclassifications of income, expenditure and affect net income and expenditure.

Following the end of the financial year, and understanding that there were no longer restrictions on the PEP-GEN shares held, the Charity made the decision to sell these in 2025-26.

Reserves

The Board has carefully reviewed the year-end position and is satisfied that reserves remain appropriate for the size and scope of the charity's operations.

The Charity holds an appropriate level of reserves which provides a level of working capital that protects the continuity of core projects under the Charity's objectives for at least six months, during which a reorganisation and review will be taken. This figure, at the end of 2024-25, is £171,351. The methodology used to calculate these core operational costs shall be presented along with the budget each year.

Unrestricted free reserves at the year-end are £322,597, down from £519,814 in March 2024, and restricted reserves are £112,694, up from £nil in March 2024.

Grant making policy
Previously we have made grants to research towards finding viable treatments and ultimately curing Duchenne Muscular Dystrophy. Moving forward, our focus will be on providing support. We recognise that other organisations in the Duchenne space focus heavily on research, and this is therefore not the best use of our expertise or funds.

We have, and will continue, to provide grants of up to £100 to families joining our international conference, as this is our community-focused event, and we do not want finances to be a barrier to accessing this wonderful event. These grants are available to cover transport and accommodation, and the event itself is free for those living with Duchenne and their family.

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.

Internal control and processes
This year the Trustees reviewed all controls and processes in place, including the delegation of authority. The controls and processes include:

- Financial controls on levels required for tenders, dual authorisation, budgetary management, monthly management accounts and fund management;
- Deadlines for regulators and funders are abided by, such as the Charity Commission and Companies House reporting procedures;
- Training logs for all Trustees and Staff, including annual safeguarding and data protection, and further training specific to roles; and
- Policy review log to ensure policies are reviewed at least every three years, with any legal updates added when required.

These measures reflect the Board's continued focus on strengthening compliance, safeguarding culture and transparent oversight.

The Board of Trustees meet face to face or via remote conferencing at least six times a year. While the Charity aims to involve parents and those living with Duchenne Muscular Dystrophy as members of the Board of Trustees, a balance is sought by recruiting non-family members who have other scientific, business, and professional expertise.

Statement of responsibilities of the trustees
The trustees (who are also directors of the charity for the purposes of company law) are responsible for preparing the trustees' report and the financial statements in accordance with 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).

The Trustees have had due regard to the Charity Commission's guidance on public benefit and have considered the major risks faced by the charity, including conflicts of interest and accepting donations, and have put systems in place to mitigate these. The Charity's fundraising practices are also compliant with the Fundraising Regulator.

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 charity and of the income and expenditure of the charity for that period. In preparing those 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 judgements and accounting estimates that are reasonable and prudent;
- state whether applicable UK accounting standards and statements of recommended practice 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 charity will continue in operation.

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

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are 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 auditors are 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

Godfrey Wilson Limited were appointed as auditors to the charitable company during the year and have expressed their willingness to continue in that capacity.

Approved by the trustees on 11 December 2025 and signed on their behalf by

Vicky Pleydell

Dr Vicky Pleydell - Chair

Independent auditors' report

To the members of

Action Duchenne Limited

Opinion

We have audited the financial statements of Action Duchenne Limited (the 'charity') for the year ended 31 March 2025 which comprise the statement of financial activities, balance sheet, statement of cash flows 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 March 2025 and of its incoming resources and application of resources, including its income and expenditure, 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 Companies Act 2006 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 the provisions available for small entities, in the circumstances set out in note 9 to the financial statements, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

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

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

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

Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. 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.

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.

Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report, which includes the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within the trustees' report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

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

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

Responsibilities of the trustees

As explained more fully in the trustees' responsibilities statement set out in the trustees' report, 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 the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Independent auditors' report

To the members of

Action Duchenne Limited

Our responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

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

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The procedures we carried out and the extent to which they are capable of detecting irregularities, including fraud, are detailed below:

(1) We obtained an understanding of the legal and regulatory framework that the charity operates in, and assessed the risk of non-compliance with applicable laws and regulations. Throughout the audit, we remained alert to possible indications of non-compliance.

(2) We reviewed the charity's policies and procedures in relation to:

- Identifying, evaluating and complying with laws and regulations, and whether they were aware of any instances of non-compliance;
- Detecting and responding to the risk of fraud, and whether they were aware of any actual, suspected or alleged fraud; and
- Designing and implementing internal controls to mitigate the risk of non-compliance with laws and regulations, including fraud.

(3) We inspected the minutes of trustee meetings.

(4) We enquired about any non-routine communication with regulators and reviewed any reports made to them.

(5) We reviewed the financial statement disclosures and assessed their compliance with applicable laws and regulations.

(6) We performed analytical procedures to identify any unusual or unexpected transactions or balances that may indicate a risk of material fraud or error.

(7) We assessed the risk of fraud through management override of controls and carried out procedures to address this risk. Our procedures included:

- Testing the appropriateness of journal entries;
- Assessing judgements and accounting estimates for potential bias;
- Reviewing related party transactions; and
- Testing transactions that are unusual or outside the normal course of business.

Independent auditors' report

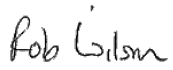
To the members of

Action Duchenne Limited

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. Irregularities that arise due to fraud can be even harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

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 members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and to the charity's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006.. Our audit work has been undertaken so that we might state to the charity's members 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 members as a body, for our audit work, for this report, or for the opinions we have formed.



Date: 11 December 2025

Robert Wilson FCA
(Senior Statutory Auditor)

For and on behalf of:
GODFREY WILSON LIMITED
Chartered accountants and statutory auditors
5th Floor Mariner House
62 Prince Street
Bristol
BS1 4QD

Action Duchenne Limited

Statement of financial activities *(incorporating an income and expenditure account)*

For the year ended 31 March 2025

	Note	Restricted £	Unrestricted £	**2025 Total £**	Restated 2024 Total £
Income from:					
Donations	3	-	174,359	**174,359**	214,217
Charitable activities	4	169,657	232,861	**402,518**	388,383
Other trading activities	5	-	4,080	**4,080**	-
Investments		-	9,566	**9,566**	9,779
Total income		169,657	420,866	**590,523**	612,379
Expenditure on:					
Raising funds		-	139,346	**139,346**	115,267
Charitable activities		56,963	477,456	**534,419**	527,091
Total expenditure	7	56,963	616,802	**673,765**	642,358
Net gains / (losses) on investments		-	(142,062)	**(142,062)**	23,507
Net income / (expenditure) and net movements in funds	9	112,694	(337,998)	**(225,304)**	(6,472)
Reconciliation of funds:					
Total funds brought forward		-	678,152	**678,152**	684,624
Total funds carried forward		112,694	340,154	**452,848**	678,152

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 18 to the accounts.

Prior period income and expenditure have been reclassified to reflect the requirements of the Charities SORP (FRS 102) and to be comparable with the current year. The restatements are to the value of financial investments, and reclassifications of income, expenditure and affect net income and expenditure. The restatements are disclosed in note 20 to the accounts.

Action Duchenne Limited

Balance sheet

As at 31 March 2025

	Note	£	2025 £	Restated 2024 £
Fixed assets				
Tangible assets	12		**2,901**	1,620
Investments	13		**14,656**	156,718
			17,557	158,338
Current assets				
Debtors	14	**122,678**		62,368
Cash at bank and in hand		**469,731**		534,978
		592,409		597,346
Liabilities				
Creditors: amounts falling due within 1 year	15	**(157,118)**		(77,532)
Net current assets			**435,291**	519,814
Net assets	17		**452,848**	678,152
Funds	18			
Restricted funds			**112,694**	-
Unrestricted funds				
General funds			**340,154**	678,152
Total charity funds			**452,848**	678,152

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

Approved by the trustees on 11 December 2025 and signed on their behalf by

Vicky Pleydell

Dr Vicky Pleydell - Chair

Action Duchenne Limited

Statement of cash flows

For the year ended 31 March 2025

	2025	Restated 2024
	£	£
Cash used in operating activities:		
Net movement in funds	**(225,304)**	(6,472)
Adjustments for:		
Depreciation charges	**1,080**	541
Losses / (gains) on investments	**142,062**	(23,507)
Dividends, interest and rents from investments	**(9,566)**	(9,779)
Loss on the sale of fixed assets	**338**	-
Increase in debtors	**(60,310)**	(55,420)
Increase / (decrease) in creditors	**79,586**	(5,203)
Net cash used in operating activities	**(72,114)**	(99,840)
Cash flows from investing activities:		
Dividends, interest and rents from investments	**9,566**	9,779
Purchase of tangible fixed assets	**(2,699)**	-
Net cash provided by investing activities	**6,867**	9,779
Decrease in cash and cash equivalents in the year	**(65,247)**	(90,061)
Cash and cash equivalents at the beginning of the year	**534,978**	625,039
Cash and cash equivalents at the end of the year	**469,731**	534,978

The charity has not provided an analysis of changes in net debt as it does not have any long term financing arrangements.

1. Accounting policies

a) General information and basis of preparation

Action Duchenne Limited is a charitable company limited by guarantee registered in England and Wales (company number: 04899036), and registered as a charity with the Charities Commission (charity number 1101971), and in Scotland (charity number SC043852) The registered office address is 5th Floor, Mariner House, 62 Prince Street, Bristol, BS1 4QD.

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) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Action Duchenne Limited meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note.

b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern, which the trustees consider appropriate having regard to the current level of unrestricted reserves. There are no material uncertainties about the charity's ability to continue as a going concern.

c) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from the government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Income received in advance of provision of sponsorship benefits is deferred until criteria for income recognition are met.

d) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity: this is normally upon notification of the interest paid or payable by the bank.

e) Funds accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

1. Accounting policies (continued)

f) Expenditure

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

g) Allocation of support and governance costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Governance costs are the costs associated with the governance arrangements of the charity, including the costs of complying with constitutional and statutory requirements and any costs associated with the strategic management of the charity's activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities based on the proportion of total costs of each activity as follows:

	2025	2024
Raising funds	**20.7%**	17.9%
Charitable activities	**79.3%**	82.1%

h) Tangible fixed assets

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

Computer equipment	4 years

Items of equipment are capitalised where the purchase price exceeds £500.

i) Financial investments

Investments are a form of basic financial instrument and are initially recognised at their transaction value and subsequently measured at their fair value as at the balance sheet date using the closing quoted market price.

All realised gains and losses are taken to the Statement of Financial Activities as they arise. Realised gains and losses on investments are calculated as the difference between sales proceeds and their opening carrying value or their purchase value if acquired subsequent to the first day of the financial year. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value. Realised and unrealised investment gains and losses are combined in the Statement of Financial Activities.

j) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

k) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

1. Accounting policies (continued)

l) Creditors

Creditors and provisions are recognised 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 discounts due.

m) Financial instruments

The charitable company only has financial assets and financial 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 with the exception of bank loans which are subsequently recognised at amortised cost using the effective interest method.

n) Pension costs

The company operates a defined contribution pension scheme for its employees. There are no further liabilities other than that already recognised in the SOFA.

o) Accounting estimates and key judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying values of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

The key sources of estimation uncertainty that have a significant effect on the amounts recognised in the financial statements are depreciation as described in note h), and financial investments as described in note i) above.

2. Prior period comparatives: statement of financial activities

	Restricted £	Unrestricted £	Restated 2024 Total £
Income from:			
Donations	-	214,217	214,217
Charitable activities	179,147	209,236	388,383
Investments	-	9,779	9,779
Total income	179,147	433,232	612,379
Expenditure on:			
Raising funds	-	115,267	115,267
Charitable activities	250,367	276,724	527,091
Total expenditure	250,367	391,991	642,358
Net gains on investments	-	23,507	23,507
Net income / (expenditure) and net movement in funds	(71,220)	64,748	(6,472)

3. Income from donations

	Restricted £	Unrestricted £	**2025 Total £**	Restated 2024 Total £
One off and event donations	-	135,147	**135,147**	180,356
Regular donations	-	36,962	**36,962**	33,861
Grants	-	2,250	**2,250**	-
Total income from donations	-	174,359	**174,359**	214,217

All income from donations in the prior year was unrestricted.

4. Income from charitable activities

	Restricted £	Unrestricted £	**2025 Total £**
Conference income	-	231,580	**231,580**
Grants	169,657	-	**169,657**
Consultancy	-	1,281	**1,281**
Total income from charitable activities	169,657	232,861	**402,518**

Prior period comparative:

	Restricted £	Unrestricted £	Restated 2024 Total £
Conference income	-	209,236	209,236
Grants	179,147	-	179,147
Total income from charitable activities	179,147	209,236	388,383

5. Income from other trading activities

	Restricted £	Unrestricted £	**2025 Total £**	Restated 2024 Total £
Conference exhibitors	-	4,080	**4,080**	-

6. Income from other trading activities

The charitable company receives government grants, defined as funding from the National Lottery to fund charitable activities. The total value of such grants in the period ending 31 March 2025 was £28,207 (2024: £135,819). There are no unfulfilled conditions or contingencies attaching to these grants in 2024/25.

7. Total expenditure

	Raising funds £	Charitable activities £	Support and governance costs £	**2025 Total £**
Donation platform fees	12,042	-	-	**12,042**
Other raising funds costs	6,276	-	-	**6,276**
Staff costs (note 10)	81,949	274,335	11,628	**367,912**
Project delivery	-	30,536	-	**30,536**
Conference	-	141,685	-	**141,685**
Audit and accountancy	-	-	26,078	**26,078**
Office costs	-	-	15,863	**15,863**
Professional fees	17,532	5,227	32,011	**54,770**
IT costs	-	-	5,429	**5,429**
Depreciation	-	-	1,080	**1,080**
General travel and subsistence	-	-	4,951	**4,951**
Other staff costs	-	-	3,955	**3,955**
Insurance	-	-	2,006	**2,006**
Trustee costs	-	-	1,182	**1,182**
Sub-total	117,799	451,783	104,183	**673,765**
Allocation of support and governance costs	21,547	82,636	(104,183)	**-**
Total expenditure	**139,346**	**534,419**	**-**	**673,765**

Total governance costs were £13,302 (2024: £8,234)

7. Total expenditure (continued)

Prior period comparative - restated

	Raising funds £	Charitable activities £	Support and governance costs £	2024 Total £
Donation platform fees	12,663	-	-	12,663
Other raising funds costs	13,069	-	-	13,069
Staff costs (note 10)	75,874	254,000	10,766	340,640
Research grants (note 8)	-	21,180	-	21,180
Project delivery	-	46,065	-	46,065
Conference	-	134,692	-	134,692
Audit and accountancy	-	-	20,856	20,856
Office costs	-	-	16,446	16,446
Professional fees	1,050	13,488	9,029	23,567
IT costs	-	-	6,621	6,621
Depreciation	-	-	541	541
General travel and subsistence	-	-	3,372	3,372
Other staff costs	-	-	966	966
Insurance	-	-	1,666	1,666
Trustee costs	-	-	14	14
Sub-total	102,656	469,425	70,277	642,358
Allocation of support and governance costs	12,611	57,666	(70,277)	-
Total expenditure	115,267	527,091	-	642,358

Prior period expenditure has been reclassified to reflect requirements of the Charities SORP and to be comparable with the current year. These are purely reclassifications and do not effect net expenditure.

8. Grant payable

Grants are made for the purpose of distributing research grants. The amounts payable and committed in the period comprise the following:

	2025 No.	**2025 £**	2024 No.	2024 £
Grants				
Grants to institutions:				
University of Glasgow	**-**	**-**	2	21,180

There were no grants paid to individuals in the current or prior year.

9. Net movement in funds

This is stated after charging:

	2025	2024
	£	£
Depreciation	**1,080**	541
Trustees' remuneration	**Nil**	Nil
Trustees' reimbursed expenses	**1,058**	14
Auditors' remuneration (excluding VAT):		
▪ Statutory audit	**10,100**	6,750
▪ Prior period under accrual	**-**	100

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

10. Staff costs and numbers

Staff costs were as follows:

	2025	2024
	£	£
Salaries and wages	**323,701**	308,523
Social security costs	**23,792**	24,424
Pension costs	**20,419**	7,693
	367,912	340,640

	2025	2024
Employees earning more than £60,000 during the year:	**No.**	No.
Between £70,000 and £80,000	**1**	1

The key management personnel of the charitable company comprise the Trustees, and senior management team. The total employee benefits of the key management personnel were £170,552 (2024: £162,023).

	2025	2024
	No.	No.
Average head count	**11.58**	9.75

11. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

12. Tangible fixed assets

	Computer equipment £	Office equipment £	**Total £**
Cost			
At 1 April 2024	2,772	1,425	**4,197**
Additions in year	2,699	-	**2,699**
Disposals	-	(1,425)	**(1,425)**
At 31 March 2025	5,471	-	**5,471**
Depreciation			
At 1 April 2024	1,603	974	**2,577**
Charge for the year	967	113	**1,080**
On disposals	-	(1,087)	**(1,087)**
At 31 March 2025	2,570	-	**2,570**
Net book value			
At 31 March 2025	**2,901**	**-**	**2,901**
At 31 March 2024	1,169	451	1,620

13. Investments

	2025 £	Restated 2024 £
Market value at 1 April	**156,718**	133,211
Gains / (losses)	**(142,062)**	23,507
Market value at 31 March	**14,656**	156,718

14. Debtors

	2025 £	2024 £
Trade debtors	**960**	32,574
Prepayments	**87,085**	24,039
Accrued income	**27,664**	-
Other debtors	**6,969**	5,755
	122,678	62,368

15. Creditors: amounts falling due within 1 year

	2025	2024
	£	£
Trade creditors	**84,976**	4,803
Accruals	**43,304**	9,708
Deferred income (note 16)	**18,000**	51,546
Other taxation and social security	**4,825**	7,146
Other creditors	**6,013**	4,329
	157,118	77,532

16. Deferred income

	2025	2024
	£	£
At 1 April	**51,546**	51,965
Deferred during the year	**18,000**	51,546
Released during the year	**(51,546)**	(51,965)
At 31 March	**18,000**	51,546

Deferred income relates to sponsorship income received in advance.

17. Analysis of net assets between funds

	Restricted funds	General funds	**Total funds**
	£	£	**£**
Tangible fixed assets	-	2,901	**2,901**
Investments	-	14,656	**14,656**
Current assets	112,694	479,715	**592,409**
Current liabilities	-	(157,118)	**(157,118)**
Net assets at 31 March 2025	**112,694**	**340,154**	**452,848**

Prior period comparative	Restricted funds	General funds	Total funds
	£	£	£
Tangible fixed assets	-	1,620	1,620
Investments	-	156,718	156,718
Current assets	-	597,346	597,346
Current liabilities	-	(77,532)	(77,532)
Net assets at 31 March 2024	-	678,152	678,152

18. Movements in funds

	At 1 April 2024 £	Income £	Expenditure £	Gains / (losses) £	**At 31 March 2025 £**
Restricted funds					
Albert Gubay	-	60,000	(7,079)	-	**52,921**
Pfizer	-	35,075	(20,059)	-	**15,016**
Sarepta	-	30,000	(18,359)	-	**11,641**
Lottery Scotland	-	28,207	(91)	-	**28,116**
Hugh Fraser	-	5,000	-	-	**5,000**
Wave Life Sciences	-	5,000	(5,000)	-	**-**
Contact Families	-	6,375	(6,375)	-	**-**
Total restricted funds	-	169,657	(56,963)	-	**112,694**
Unrestricted funds					
General funds	678,152	420,866	(616,802)	(142,062)	**340,154**
Total unrestricted funds	678,152	420,866	(616,802)	(142,062)	**340,154**
Total funds	678,152	590,523	(673,765)	(142,062)	**452,848**

Purposes of restricted funds

Albert Gubay

This project funds counselling activities and peer support for families and people living with Duchenne, alongside building relationships with providers of, and highlighting the importance of, palliative and end of life care.

Pfizer

This project funds training for young people living with Duchenne as they become adults, including increasing independence and further study or job opportunities.

Sarepta

This project funds activities for children and young people living with Duchenne as they become adults, including increasing independence, training, information and social events.

Lottery Scotland

This project funds our core All Through Support work with families across Scotland, including 1:1 support, peer networks, workshops, schools training and ensuring families are comfortable making informed decisions about care decisions and end of life support.

Hugh Fraser

This project specifically funds activities for Scotland-based children and young people living with Duchenne as they become adults, including increasing independence, training, information and social events.

18. Movements in funds (continued)

Purposes of restricted funds (continued)

Wave Life Sciences

This project enabled us to carry out our core activity of supporting families through diagnosis, and helping them making informed decisions.

Contact Families

This project originally funded peer-to-peer support groups, which are now part of Action Duchenne's core activity.

Prior period comparative - restated

	At 1 April 2023 £	Income £	Expenditure £	Gains / (losses) £	At 31 March 2024 £
Restricted funds					
National Lottery Fund	29,462	135,819	(165,281)	-	-
Supporting Families	7,540	7,700	(15,240)	-	-
Contact a Family	15,138	4,360	(19,498)	-	-
Transition to Adulthood	19,080	31,268	(50,348)	-	-
Total restricted funds	71,220	179,147	(250,367)	-	-
Unrestricted funds					
General funds	613,404	433,232	(391,991)	23,507	678,152
Total unrestricted funds	613,404	433,232	(391,991)	23,507	678,152
Total funds	684,624	612,379	(642,358)	23,507	678,152

19. Related party transactions

During the year, 3 trustees made unrestricted donations totalling £651 (2024: £nil). There were no unfilled conditions or amounts outstanding at the year end.

20. Restatement of prior year balances

Pepgen shares

To recognise the market value of the shares held by the charity in the prior year and the gains / (losses) incurred.

Halo Therapeutics convertible loan note

Prior period financial statements included a convertible loan note in Halo Therapeutics LLC issued in 2012, funded by a restricted grant received in previous years. As of 31 March 2023, the convertible loan note was deemed irrecoverable due to no communication being available with Halo Therapeutics and multiple changes of entity since the loan was issued. The restatement below is to derecognise the convertible loan note as at 1 April 2023.

20. Restatement of prior year balances (continued)

	2024 £
Original net book value of convertible loan as at 1 April 2023	1
Derecognition of irrecoverable loan note	(225,000)
Derecognition of grant allocation	224,999
Adjusted net book value of convertible loan as at 1 April 2023	-

	2024 £
Original investments as at 1 April 2023	2
Recognition adjustment of the fair value of the shares as at 1 April 2023	133,210
Irrecoverable Halo Therapeutics convertible loan	(1)
Adjusted investments as at 1 April 2023	133,211

	2024 £
Original opening funds as at 1 April 2023	551,415
Recognition adjustment of the fair value of the shares as at 1 April 2023	133,210
Irrecoverable Halo Therapeutics convertible loan	(1)
Adjusted opening funds as at 1 April 2023	684,624

	2024 £
Original gains and losses on investments	-
Gain on investment of Pepgen shares	23,507
Original gains and losses on investments	23,507

	2024 £
Original investments as at 31 March 2024	2
Recognition adjustment of the fair value of the shares as at 1 April 2023	133,210
Irrecoverable Halo Therapeutics convertible loan	(1)
Gain on investment of Pepgen shares	23,507
Adjusted investments as at 31 March 2024	156,718

ACTION DUCHENNE LIMITED

England & Wales - Charity number 1101971

Accounts

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 MARCH 2024

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ADMINISTRATIVE AND STATUTORY DETAILS

Board of Trustees	Mark Silverman Gary Fegan Roger Cockerton (Treasurer) Emma Simmonds Anna Mabile Greg Hill Dr Victoria Pleydell
Chief Executive Officer	Florence Boulton
Scientific Advisory Board	Dame Professor K Davies – Chair Professor M Wood – Vice Chair
Registered office	Wellesley House Duke of Wellington Avenue Royal Arsenal London SE18 6SS
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

MESSAGE FROM THE CHIEF EXECUTIVE OFFICER
FOR THE YEAR ENDED 31 MARCH 2024



As we end another year at Action Duchenne, I am deeply proud of all we have achieved together. It has been a year of growth and progress, as we faced challenges while staying true to our mission: creating a world where Duchenne muscular dystrophy no longer limits lives.

Our updated strategy, approved by the Board of Trustees in March 2024, reflects our renewed commitment to the Duchenne community. We promise to keep providing hope, support, and advocacy, and we are determined to make the coming years transformative for everyone affected.

One of our biggest successes this year has been the growth of our 'All-through Support' programme, [Our Impact - Action Duchenne] which has become a vital lifeline for families newly diagnosed with Duchenne. Knowing how overwhelming a diagnosis can be, we've worked hard to offer tailored support from the outset. Our team made 885 contacts, expanded regional support with 44 groups, and launched 4 new group counselling sessions. We partnered with 7 clinics to support 82 newly diagnosed families, ensuring no one feels alone. Additionally, 69 young people joined our transition to adulthood programme, building key skills and peer networks.

Alongside our support efforts, we've made great progress in research and education. We continue to invest in cutting-edge research, from genome editing to new treatments. This year, we maintained support for key projects, expanded our educational workshops to 23 locations, and created 48 bite-sized science videos for the community. These workshops help families make informed decisions about treatment and care. As new scientific advances bring hope, we remain committed to ensuring the Duchenne community has access to the latest information and therapies.

"Action Duchenne provides a safe space where we come together each year. The Annual International Conference offers a chance to step away from daily life, connect with others, share experiences, find support, and have fun in a fully accessible environment."



A highlight of 2023 was our November conference which brought together over 300 families, clinicians, researchers, and industry leaders. With 26 sessions on research and practical advice, it remains one of Europe's largest Duchenne-focused events. Patron Harry Hill also presented the AD Champion Awards, recognising our key supporters. The event reinforced the importance of uniting our community and advancing these vital conversations.

We've made great progress in clinical trials and treatment reviews, which are vital for developing new therapies and improving outcomes for people with Duchenne. This year, Action Duchenne has worked closely with researchers, pharmaceutical companies, and regulators to ensure the voices of those with Duchenne are heard. Our efforts with organisations like NICE and the MHRA have been key in securing access to life-changing treatments for many in our community.

"Fundraising remains vital, and we've been touched by our supporters' generosity. The 'Challenge 79' campaign, launched for World Duchenne Awareness Day, not only raised funds but also increased global awareness of Duchenne.

We also collaborated with UK and international organisations to raise awareness, leading to the UN's recognition of 7th September as World Duchenne Awareness Day - a testament to our ability to unite people worldwide for meaningful change."



ACKNOWLEDGEMENTS

As we celebrate these achievements, I want to take a moment to acknowledge that none of this would have been possible without the dedication and hard work of our team, trustees, volunteers, supporters, funders, and partner organisations. I am deeply grateful **to our staff,** whose commitment and passion drive our mission forward every day. Your hard work and dedication are the foundation of everything we accomplish. **To our trustees and Patrons,** your wisdom, guidance, and leadership have been invaluable in helping us navigate the challenges of this past year. You have played a crucial role in keeping us on course.

To our volunteers, who give so generously of their time and energy—you are the heart of our community. Your commitment to our cause is truly inspiring, and you help us reach more people than we could ever manage on our own.

To our supporters and funders, your generosity and belief in our mission have enabled us to expand our services and reach more families than ever before. Your contributions are making a real difference in the lives of those affected by Duchenne, and for that, we are profoundly thankful.

And to our partner organisations, thank you for standing with us, working with us, and amplifying our impact. Your collaboration has been crucial in moving our shared goals forward, and together we are making significant strides towards a future where lives are no longer limited by Duchenne.

LOOKING AHEAD

Our vision for the next 10 years is clear: a world where Duchenne is no longer life-limiting, and everyone affected has access to the care, treatments, and support they need to live full lives. Achieving this will take continued effort, innovation, and collaboration, but I'm confident we will keep moving forward together.

Our 'All-through Support' programme remains a priority, providing tailored guidance and care for those affected by Duchenne at every stage of life.

"We're committed to adapting this support as the community's needs evolve. We'll also keep investing in research and supporting innovative projects to change the future of Duchenne, while expanding educational resources to give families the knowledge they need to make informed decisions."



We will build on the success of our international conference, making it even more impactful by bringing together more voices from around the world. Clinical trials and treatment reviews will also remain a key focus as we work to ensure the best possible care for the Duchenne community.

Join me in shaping the future for those affected by Duchenne. Stay engaged, support our mission, and explore new opportunities to collaborate. Together, we can create a better future for everyone living with Duchenne.

.....

Florence Boulton
Chief Executive Officer
Date:

The Trustees present their report and the financial statements for the twelve months ended 31 March 2024 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 2019).

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 Wellesley House, Duke of Wellington Avenue, Royal Arsenal, London SE18 6SS.

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:

Mark Silverman
Gary Fegan
Roger Cockerton (Treasurer)
Victoria Penrice (resigned on 29 February 2024)
Emma Simmonds (appointed 8 February 2024)
Anna Mabile (appointed 25 June 2024)
Greg Hill (appointed 25 June 2024)
Dr Victoria Pleydell (appointed 25 June 2024)

The Board is delighted to welcome three new members and express their thanks to Victoria for her contribution as charity secretary. Our new Trustees have been 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 Board would also like to thank all Patrons, staff and volunteers past and present, who have given their time and energy to Action Duchenne.

Introduction

We, the Trustees of Action Duchenne, are pleased to present our report for the year ending 31 March 2024. This past year has seen continued progress in our core work, supported by strong governance and a clear long-term vision for the charity. Our key priorities are to ensure that our financial resources, governance, and operations are well-aligned with our mission to create a world where Duchenne muscular dystrophy no longer limits lives.

Governance and leadership
Action Duchenne is governed by a Board of Trustees, who make sure the charity follows its legal, regulatory, and ethical obligations. Throughout 2023/24, the Trustees held regular meetings to oversee the charity's work, monitor progress, and approve key plans.

This year, we were delighted to welcome three new Trustees—Anna Mabile, Greg Hill, and Dr. Victoria Pleydell—who bring valuable experience in research, finance, and healthcare. Their expertise strengthens our leadership team as we prepare for the next stage of our development. All Trustees have been fully briefed on their responsibilities under charity and company law, and we are planning a review of our governance to ensure it remains fit for the future.

We remain committed to ensuring our Board reflects the diversity of the Duchenne community, alongside professional expertise.

Strategic oversight and long-term planning
Our long-term strategy is focused on providing lasting and meaningful support for people affected by Duchenne muscular dystrophy. As we complete our 2021-2024 strategy, we are now working on a new three-year plan. This will build on our successes while addressing the new challenges our community faces, especially in terms of access to treatments and support.

The Trustees are focused on making sure our programmes and initiatives continue to support our long-term goals. Our key areas of focus include:

- **Sustaining the 'All-through Support' programme**: Making sure we can continue to provide lifelong, tailored support to those affected by Duchenne.
- **Research and education**: Continuing to invest in high-impact research and educational initiatives that help improve treatments and care.
- **Partnerships and advocacy**: Strengthening collaborations with international partners to maintain our role as leaders in the fight for better treatments and care standards.

About us: our vision and objectives
Action Duchenne has a very clear vision: a world where lives are no longer limited by Duchenne muscular dystrophy.

We have three core objectives in the next year and are proud to spend 90.6p in every £1 raised on our charitable activities:

- Building a community by uniting and supporting families, educating about Duchenne, and raising the profile of the condition.
- Giving families, clinicians and the wider community the most accessible and up to date information in the right at the right time
- Funding impactful research and projects that make an immediate difference and campaigning for these changes.

It is clear that despite the best efforts of Action Duchenne and its partners, there is still an unmet need for support and delivering the right information at the right time. We have identified opportunities to expand our "All-through-Support" to the entire community and revamp our communications strategy and these will be major areas of focus for Action Duchenne.

Financial review

The Trustees are responsible for ensuring the financial health of the charity, and we are pleased to report that Action Duchenne is in a stable financial position.

In 2023/24 the Charity had a net deficit for the year of £29,979 following a surplus of £131,019 in the previous year. Scientific education, research, supporting families and grants payable increased by 4% from £508,861 to £527,534. Cost of events and general fundraising increased by 69% from £35,725 to £60,446, which compounded the deficit for the year

Income for the year totalled £612,379, this is a decrease of 14% on the previous year (£711,864 in 2023), with amounts generated from donations and legacies decreasing 12% to £257,546 for the year (£293,483 in 2023), income from other trading activities, increasing 30% to £209,235 for the year (£160,911 in 2023) and a decrease of 47% to £135,819 (£257,442 in 2023) in income from charitable activities.

Expenditure on charitable activities was £581,912 in the year (2023: £545,120), including allocated support costs. This represents 90.6% of total expenditure, compared to 93.9% in the previous year. As well as the research organisations listed above, this includes Eurordis membership, World Duchenne Organisation membership and Genetic Alliance UK membership.

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 six months of charity expenditure of £207,700, 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 at the year-end are £521,436, up from £480,195 in March 2023; and restricted reserves are £nil (2023: £71,220). 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. Our research strategy sets out five areas, where we will focus our investment in research going forward:

- Innovation – we will co-fund novel research projects
- Outcome measures and natural history data
- Investing in tissue collection and biobanking
- Standards of Care – continuing our long-standing involvement in supporting the best possible multidisciplinary standards of care
- Maintaining the UK DMD Registry

The rapidly changing developments in international research demand a constant updating of the Charity's grant making policy. Our peer reviews grant applications as part of a two-stage review process and systematically reviews and agrees its research and grant making policy during the development of its annual business plan.

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, funds were split and placed on short term time deposits with different end dates to enable easy access to funds.

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.

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:

- 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 from the National Director and then the Finance Committee and/or the board of Trustees
- The management team prepare a business plan with internally audited yearly accounts and projections of budget expenditure at the end of each year. This is fully discussed by the Finance Committee and then at a specially convened meeting of the Board of Trustees
- Chain of command overseen by the Treasurer, 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
- Charity procedures (including financial control)
- Equality, diversity and inclusion
- Social media and digital/electronic communications

The Board of Trustees meet face to face or via remote conferencing at least four times a year. While the Charity aims to involve parents and those living with Duchenne muscular dystrophy as members of the Board of Trustees, a balance is sought by recruiting non-family members who have other scientific, business, and professional expertise. The Board is supported by four committees, each with specific terms of reference: corporate engagement, audit, finance & risk, delivery & research, and conference.

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.

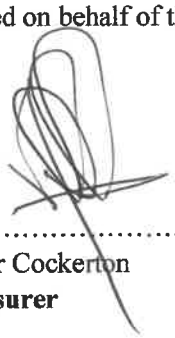
Auditor
Simpson Wreford LLP were reappointed as Auditor during the year and have expressed their willingness to continue in that capacity.

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.

Looking Ahead
Looking forward, the Trustees are committed to building on our successes and ensuring the charity remains sustainable for the long term. Our next phase of development will focus on maintaining financial stability, expanding our support services, and continuing to lead the way in research and advocacy for the Duchenne community.

We will work closely with the management team to monitor progress and make sure we achieve our goals while maintaining strong governance and financial health.

Signed on behalf of the Board of Directors.



.....
Roger Cockerton
Treasurer

Date: 18 October 2024

Opinion

We have audited the financial statements of Action Duchenne Limited (the 'Charitable company') for the year ended 31 March 2024 which comprise the Statement of Financial Activities, Statement of Financial Position, 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 March 2024 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 Companies Act 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.

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 Companies Act 2006 requires us to report to you if, in our opinion:

- adequate 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;
- we have not obtained all the information and explanations necessary for the purposes of our audit;
- the directors 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 directors' 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 page 10, the Trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as 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 Charitable company'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.

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 Act 2011 rather than the Companies Act 2006. Accordingly, 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 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 auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements. A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities]. This description forms part of our auditor's report.

Extent to which the audit was considered capable of detecting irregularities, including fraud

- the engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities, and skills to identify or recognise non-compliance with applicable laws and regulations;
- we identified the laws and regulations applicable to the Charitable company through discussions with directors and other management, and from our commercial knowledge and experience of membership organisations and support services sector;
- we focused on specific laws and regulations which we considered may have a direct material effect on the financial statements or the operations of the Charitable company, including the Companies Act 2006, data protection and Arts Council regulations;
- we assessed the extent of compliance with the laws and regulations identified above through making enquiries of management and inspecting legal correspondence; and
- identified laws and regulations were communicated within the audit team regularly and the team remained alert to instances of non-compliance throughout the audit.

Audit response to risks identified

We assessed the susceptibility of the Charitable company's financial statements to material misstatement, including obtaining an understanding of how fraud might occur, by:

- making enquiries of management as to where they considered there was susceptibility to fraud, their knowledge of actual, suspected, and alleged fraud; and
- considering the internal controls in place to mitigate risks of fraud and non-compliance with laws and regulations.

To address the risk of fraud through management bias and override of controls, we:

- performed analytical procedures to identify any unusual or unexpected relationships;
- tested journal entries to identify unusual transactions;
- assessed whether judgements and assumptions made in determining the accounting estimates were indicative of potential bias; and
- investigated the rationale behind significant or unusual transactions.

In response to the risk of irregularities and non-compliance with laws and regulations, we designed procedures which included, but were not limited to:

- agreeing financial statement disclosures to underlying supporting documentation and;
- enquiring of management as to actual and potential litigation and claims.
- reviewing correspondence with regulators.

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the directors and other management and the inspection of regulatory and legal correspondence, if any.

Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

Use of our report

This report is made solely to the Charitable company's members, as a body, in accordance with Chapter 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Charitable company's members 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 Charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Michael Broder, Senior Statutory Auditor

For and on behalf of Simpson Wreford LLP, Statutory Auditor

Wellesley House

Duke of Wellington Avenue

Royal Arsenal

London

SE18 6SS

Dated: 5 NOVEMBER 2024

Simpson Wreford LLP is eligible to act as an auditor in terms of 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 MARCH 2024

	Notes	2024 Unresticted funds	2024 Restricted funds	2024 Total funds	2023 Total funds
Income and endowments from:	4				
Donations and legacies		214,218	43,328	257,546	293,483
Charitable activities		-	135,819	135,819	257,442
Other trading activities		209,235	-	209,235	160,911
Investments		9,779	-	9,779	28
Other - Government grants		-	-	-	-
Total income		**433,232**	**179,147**	**612,379**	**711,864**
Expenditure on:	15				
Raising funds:					
Cost of events and general fundraising		60,446	-	60,446	35,725
Charitable activities:					
Campaigning and education,		208,384	85,086	293,470	128,208
Research, supporting families, and grants payable		68,783	165,281	234,064	380,653
Improved management and medical care		54,378	-	54,378	36,259
Total expenditure		**391,991**	**250,367**	**642,358**	**580,845**
Net income/(expenditure)		41,241	(71,220)	(29,979)	131,019
Transfers between funds		-	-	-	-
Net movement in funds		**41,241**	**(71,220)**	**(29,979)**	**131,019**
Reconciliation of funds:					
Balance at 1 April 2023		480,195	71,220	551,415	420,396
Balance at 31 March 2024		**521,436**	-	**521,436**	**551,415**

The notes on pages 18 to 27 form part of these financial statements.

ACTION DUCHENNE LIMITED

STATEMENT OF FINANCIAL POSITION
AS AT 31 MATCH 2024

	Notes	2024		2023	
		£	£	£	£
Fixed assets					
Tangible assets	**5**		1,620		2,161
Investments	**6**		2		2
			1,622		2,163
Current assets					
Debtors	**7**	62,368		6,948	
Cash at bank and in hand	**18**	534,978		625,039	
		597,346		631,987	
Current liabilities					
Creditors due within one year	**8**	(77,532)		(82,735)	
Net current assets			519,814		549,252
Total assets less current liabilities			521,436		551,415
Net assets	**17**		**521,436**		**551,415**
Represented by:					
Restricted funds	**12**		-		71,220
Unrestricted funds	**13**		521,436		480,195
			521,436		**551,415**

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the period ended 31 March 2024. 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.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

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 15 - 27 were approved by the Trustees on 18/12/24 and signed on their behalf by:

.....
Roger Cockerton – **Trustee/Treasurer**

Registered charity number – 1101971
Registered charity – SC043852 (Scotland)

ACTION DUCHENNE LIMITED

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 31 MARCH 2024

	Notes	2024 Total £	2023 Total £
Cashflows from operating activities:			
Net cash provided by operating activities	17	(99,840)	194,066
Cashflows from investing activities:			
Dividends, interest, and rents from investments		9,779	28
Purchase of equipment		-	-
Proceeds from disposal of tangibles		-	-
Net cash (used in) by investing activites		9,779	28
Cashflows from financing activities:			
Loan received		-	-
Interest paid		-	(719)
Net cash (used in)/provided by financing activites		-	(44,264)
Change in cash and cash equivalents in the reporting period		(90,061)	149,111
Cash and cash equivalents as at 1 April 2023		625,039	475,928
Cash and cash equivalents as at 31 March 2024		**534,978**	**625,039**

1. Accounting policies

a) Company information – Action Duchenne Limited is a private company limited by guarantee, incorporated in England and Wales (Company Registration Number: 04899036) and registered as a charity with the Charities Commission (Registered Charity Number: 1101971) and in Scotland (Registered Charity Number – Scotland: SC043852). The principal and registered office is Wellesley House, Duke of Wellington Avenue, Royal Arsenal, London SE18 6SS.

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 2019) - (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 twelve months ended 31 March 2024 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 March 2024 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 15 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 auditors' fees.

1. Accounting policies (continued)

h) Programme related investments are included in the accounts at cost less amounts written off as grants payable.

i) Fixed assets are only capitalised were their values exceed £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) Redundancy payments – the Charity recognises redundancy payments relating to the early termination of an employee or group of employees immediately as an expense in the SOFA when there is a legal or constructive obligation to pay it.

1. Accounting policies (continued)

s) 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.

2. Employees

Costs to the company were as follows:

	2024 £	2023 £
Gross wages:		
- projects	266,713	242,636
- non-projects	41,810	26,615
Staff pension	7,693	5,847
Employer's NI contributions	24,424	19,901
	340,640	294,999

The defined contribution expense is allocated between restricted and unrestricted funds in accordance with the allocation of wages and salaries costs.

There was one employee at Action Duchenne Limited whose remuneration exceeded £60,000.

During the year redundancy payments totalling £nil (2023: £nil) were made to employees.

The average number of full-time employees during the year was 9.75 (2023: 9) analysed as follows:

	2024 Number	2023 Number
Management - FTE	1.0	1.0
Research - FTE	1.0	1.0
Supporting families - FTE	5.35	5.5
Fundraising - FTE	1.6	1.2
Advocacy/Campaigns - FTE	0.8	0.3
	9.75	9.0

3. Net incoming resources is stated after charging

	2024 £	2023 £
Auditors' fees	8,100	7,800
Independent examination and accountancy fees	12,756	12,646
Depreciation	540	720

4. Analysis of income and endowments

	Unresticted funds £	Restricted funds £	2024 Total £	2023 Total £
Donations and legacies				
- Grants of a general nature	-	43,328	43,328	128,814
- Membership subscriptions	33,862	-	33,862	10,012
- Fundraising income	162,308	-	162,308	142,160
- Gift Aid	18,048	-	18,048	12,496
- Other	-	-	-	-
Charitable activities				
- Performance related grants	-	139,819	139,819	257,442
- Other	-	-	-	-
Other trading activities				
- Fundraising events	-	-	-	-
- Non-charitable trading activities	209,235	-	209,235	160,911
- Shop income	-	-	-	-
Investments	9,779	-	9,779	28
Other – Government grants	-	-	-	-
	433,232	179,147	612,379	711,864

5. Tangible assets

	Computer equipment £	Fixtures & fittings £	Office equipment £	Total £
Cost				
At 1 April 2023	2,772	-	1,425	4,197
Additions	-	-	-	-
Disposals	-	-	-	-
31 March 2024	2,772	-	1,425	4,197
Depreciation				
At 1 April 2023	1,213	-	823	2,036
Charge fpr the year	390	-	151	541
Disposals	-	-	-	-
At 31 March 2024	1,603	-	974	2,577
Net book value				
At 31 March 2024	1,169	-	451	1,620
At 31 March 2023	1,559	-	602	2,161

6. Investments

	2024 £	2023 £
Programme related investments		
Convertible loan note in Halo Therapeutics LLC	225,000	225,000
Less: treated as grant paid 2012	(224,999)	(224,999)
	1	1

Halo Therapeutics is a clinical-stage biopharmaceutical firm focused on developing innovative therapies for rare fibrotic diseases such a 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.

There has been no communication from Halo Therapeutics regarding additional financing arrangements. The Trustees are therefore unable to consider the fair value of this holding and it should remain valued at cost.

	2024 £	2023 £
Other investments		
1,371 Ordinary shares of £0.001	1	1

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.

In December 2020 PepGen Limited participated in a $45m Series A funding round led by RA Capital Management with an exchange of shares originally denominated in Sterling to US Dollars in PepGen Inc.

In August 2021 PepGen Limited announced an IPO closing of $112.5m crossover financing to advance transformative therapies for neuromuscular diseases that resulted in an increase in our shareholding originally 1,371 to 13,467. The shares are listed on NASDAQ with a value of c$9 giving an overall value to our holding of $121,203. However, there is a restriction as to when shares can be sold.

In view of the high-risk nature of this type of investment the Board has decided not to recognise the value of this holding until a decision is reached whether to keep the shares once permitted to sell them.

7. Debtors

	2024 £	2023 £
Trade debtors	32,574	4,385
Other debtors	5,755	506
Prepayments	24,039	2,057
	62,368	6,948

8. Creditors: amounts falling due within one year

	2024 £	2023 £
Trade creditors	4,803	1,062
Accruals and deferred income	61,254	78,158
Tax and social security	7,146	-
Other creditors	4,329	3,515
	77,532	82,735

Deferred income included above relates to donations totalling £nil (2023: £nil), and grant income related to the following projects: Jointly Supporting Newly Diagnosed £51,546 (2023: £16,965) and Corporate Sponsorships £nil (2023: £35,000). Donation income is deferred when it relates to a specific event taking place in the following period. Grant income is deferred in accordance with the grant documentation 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 2024, the total out-of-pocket expenses reimbursed was £483 (2023: £392) 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 auditor

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

12. Restricted funds

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

The movements for the year are as follows:

	At 1 April 2023 £	Incoming Resources £	Outgoing Resources £	Transfers £	At 31 March 2024 £
Restricted funds:					
National Lottery Fund	29,462	135,819	(165,281)	-	-
Supporting Families	7,540	7,700	(15,240)	-	-
Contact a Family	15,138	4,360	(19,498)	-	-
Transition to Adulthood	19,080	31,268	(50,348)	-	-
	71,220	179,147	(250,367)	-	-

Details of funds

National Lottery Fund – We received a grant of £480,130 from the Government, in partnership with the National Lottery Community Fund, over two years to support the 'All-through Support' programme, the first of its kind for the Duchenne community. Launched in October 2021, the programme ensures that every family facing a Duchenne diagnosis can immediately access a support network and resources during this difficult time. Additionally, a smaller grant of £8,173 was awarded in September 2023 from the All-through Support – Lottery Cost of Living Grant. The pilot programme completed in 2023/24.

Supporting Families Through Diagnosis and Impossible Decisions (previously called Science on Tour) - This project, funded by a group of pharmaceutical companies, completed its third year in March 2024. It's part of the 'All-through Support' pilot programme and helps families through difficult decisions after a Duchenne diagnosis.

Contact a Family – This project has set up peer-to-peer support groups where parents, grandparents, siblings, and those living with Duchenne can come together to share their experiences and support each other. These groups are thriving and cover important topics such as going back to school, anxiety, declining mobility, and loneliness. They provide a vital, safe space for our community.

Transition to Adulthood – Also supported by pharmaceutical companies, this project finished its second year in March 2024. It's part of the 'All-through Support' pilot programme and helps young people with Duchenne as they move into adulthood.

13. Unrestricted funds

	General Fund £
At 1 April 2023	480,195
Income	433,232
Expenditure	(391,991)
Transfer	-
At 31 March 2024	521,436

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

	Unrestricted funds £	Restricted funds £	2024 Total £	2023 Total £
Fixed assets	1,622	-	1,622	2,163
Current assets	597,346	-	597,346	631,987
Current liabilities	(77,532)	-	(77,532)	(82,735)
Non-current liabilities	-	-	-	-
	521,436	-	521,436	551,415

15. Analysis of resources expended

	2024 £	2023 £
Support costs:		
Bank charges and interest	3,951	4,226
Insurance	1,666	1,364
Wages and salaries	340,640	294,999
Printing, postage and stationery	5,935	6,282
Training, recruitment and other staff costs	31,234	35,523
Computer costs	16,531	19,550
Storage	2,838	2,561
Telephone and internet costs	4,694	4,472
Depreciation	540	720
Governance costs	20,856	20,446
Professional fees	28,311	17,600
Miscellaneous expenditure	6,296	7,102
	463,492	414,845

Support and governance costs are allocated as follows:

	Support and governance £	Direct costs £	Total £
Research, supporting families, and grants payable	212,884	21,180	234,064
Fundraising and events	52,930	7,516	60,446
Scientific education	143,300	150,170	293,470
Improved management and medical care	54,378	-	54,378
	463,492	178,866	642,358

The allocation of support and governance costs has been determined on the basis of time spent by staff.

16. 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:

	2024 £	2023 £
Grant – The Univerity of Glasgow	21,180	-
	21,180	-

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

	2024 £	2023 £
Grant to The University of Glasgow	-	10,590
	-	10,590

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

	2024 Total £	2023 Total £
Net surplus/(deficit) for the reporting period	(29,979)	131,019
Adjustments for:		
Depreciation charges	540	720
Loss on disposal of tangibles	-	-
Interest payable	-	719
Grant income related to bounce back loan	-	-
Dividends, interest, and rents from investments	(9,779)	(28)
Increase / (decrease) in debtors	(55,420)	4,101
Increase / (decrease) in creditors	(5,203)	57,535
Net cash provided by (used in) operating activites	(99,840)	194,066

18. Analysis of cash and cash equivalents

	2024 £	2023 £
Cash in hand	534,978	625,039
	534,978	625,039

19. Events after the reporting period

There are no events after the reporting date which require disclosure in the financial statements.

ACTION DUCHENNE LIMITED

England & Wales - Charity number 1101971

Accounts

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 MARCH 2023

ACTION DUCHENNE LIMITED

ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023

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ADMINISTRATIVE AND STATUTORY DETAILS

Board of Trustees	Mark Silverman Gary Fegan Roger Cockerton (Treasurer) Victoria Penrice
National Director	Florence Boulton
Scientific Advisory Board	Dame Professor K Davies – Chair Professor M Wood – Vice Chair
Registered office	Wellesley House Duke of Wellington Avenue Royal Arsenal London SE18 6SS
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

MESSAGE FROM THE NATIONAL DIRECTOR
FOR THE YEAR ENDED 31 MARCH 2023

Action Duchenne knows it will take a coordinated and sustained national and international effort to fulfil our vision: *a world where lives are no longer limited by Duchenne muscular dystrophy.*

Rebuild, refocus and reinvest

Our new strategy was established in 2020 and has three distinct and interrelated elements:

1. *Supporting Duchenne families all-through their journey – building a community by uniting and supporting families, educating about Duchenne and raising the profile of the condition*
2. *Funding research into potential therapeutic strategies for a future where lives are no longer limited by Duchenne and campaign for optimal standards of care and accessibility of treatment.*
3. *Striving for a more inclusive society, promoting the importance of human equality, day-to-day acceptance of disability and accessibility.*

We recognise we need to continue to improve how all those serving our community come together to provide what is most needed, and we are committed to working with other organisations to further enhance a cohesive shared vision for Duchenne support. Through our science education tours, our international conference and support calls we identified unmet needs: soon after families are given the diagnosis of Duchenne muscular dystrophy, it can be hard for a family to access support and they face an average of 3-6 months even until their next appointment with a clinician. This leads to immense anxiety and worry for the families about their child's future and many families struggle to cope and carry on with daily life.



We appreciate that Duchenne is a complex condition and requires a team of experts from multiple areas such as cardiology, neurology, endocrinology, to name a few. Parents feel extremely overwhelmed soon after diagnosis and struggle to come to terms with it. Many families have shared how the diagnosis has rapidly affected their quality of life; how they are up most of the night trying to do their own research and do not feel prepared for what the future holds. At Action Duchenne our mission is to be there for the families soon after diagnosis to answer the why, how, and when behind the condition, to be the shoulder to cry on, to be a trusted source to signpost families to the right resources without them having to comb through mountains of information on the internet.

Our outreach and support officers talk to 1,000+ families annually. They provide a vital support mechanism for families – we focus on helping families to live with the condition, valuable and much-needed work to the entire community. Up and down the country there are several thousand families, not just parents and siblings, but also grandparents, aunts, uncles and family friends – we help everyone throughout their Duchenne journey.

1. Support Duchenne families all-through their journey

We believe, with the appropriate support and scientific knowledge families will feel empowered and prepared to face the challenges that come with the diagnosis of Duchenne muscular dystrophy. We want to be there for the families when they need us most to provide support, answer their scientific queries and equip them with relevant and accurate information to help them make informed decisions.



Action Duchenne is committed to supporting every young person, adult and family throughout their Duchenne journey. To achieve this, we listen carefully to our community – and are led by what we hear.

Action Duchenne has been through a period of intensive change, building the capacity for us to deliver support to more individuals and families. We have looked carefully at our goals and objectives and at our ways of working, carefully considering the capabilities that we need to provide the quality support that our community deserves. In 2023 that enables us to constantly focus on:

ACTION DUCHENNE LIMITED

MESSAGE FROM THE NATIONAL DIRECTOR
FOR THE YEAR ENDED 31 MARCH 2023

1.1 Offering families diagnosed with Duchenne support immediately after diagnosis by building peer-to-peer support groups and offering specialist 1:1 support to those who need it;

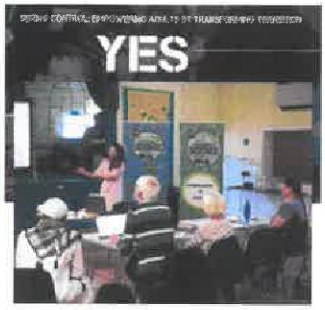
There are approximately 120 newly diagnosed Duchenne families in the UK each year, and the majority of cases were diagnosed in a small number of specialised centres. Despite being acknowledged centres of clinical excellence, they are not set up to provide the emotional, psychological and practical advice families urgently require. Providing support to these families and clinics, to improve the standards of care is one of the main purposes of our supporting parents through the diagnosis project.

In 2023 we provided a vital support mechanism for our newly diagnosed families including:



- 91 newly diagnosed contacts made from outreach to us, from community events/activities and word of mouth referrals. Links have been made with 9 specialist hospitals for families to be referred to Action Duchenne to receive support.
- 15 regional/local peer-to-peer support groups established with plans to extend our current 'Friday Hive' groups to include a 'Dads Hive' and wider families groups.
- Building on the success of our previous online events, successfully hosted the October 2022 Newly Diagnosed event designed to support 37 newly diagnosed families.

1.2 Providing unbiased, factual, life-changing information and advice to empower families to make informed decisions and champion their child;



- 20 Duchenne Science workshop delivered across the UK and Ireland.
- 118 attendees at the event with 68 new contacts with Action Duchenne made.
- 100 percent of the responses from the survey found the workshops useful.

360 of Duchenne Science: mutations, genetics, diagnosis, screening, emerging drugs, steroids, standards of care.

Testimonials from newly diagnosed families

"I felt so overwhelmed to start off with because no one is given the tools they need to do anything about this. After speaking with Action Duchenne, I learned to take care of things I can change and focus on what we considered important" - Matthew, Duchenne father.

"Specialist advice, and advocacy specific to the current difficulties we were experiencing. A shoulder to cry on, and the chance to build friendships; friendships that matter so much, when times are tough!" Ben, Duchenne father.

1.3 Supporting families – core by building online peer-to-peer support groups and regional support groups and offering families 1:1 support calls and in person meetings.



- Regional support call list has been established following return to full capacity of the support team. 1,200+ young people, adults and their families supported through our direct and bespoke support calls, video chats and messaging, and online and in person meetings.
- 17 peer-to-peer support groups have been established to ensure that people can access support in a way that suits their needs.
- Hosted 21 group support meetings, and created a new supporting schools webpage with resources for schools and parents.
- Delivered in person training to teachers and assembly talks in local schools to raise awareness of Duchenne aimed at the children as well as the staff. Over 70 teachers and 300 pupils have received Duchenne awareness information – the team have template presentations for schools and the activities can link with the Transition project and community fundraising.

Testimonials from supporting families - core

"Action Duchenne provided a vital support mechanism for my wife and I after my son was diagnosed with Duchenne Muscular Dystrophy six years ago, soon after he turned four. It made a huge difference to have people we could talk to, who not only understood what we were going through, but could also provide valuable advice on all aspects of managing the condition, from dealing with the emotional side of being newly diagnosed and loss of the ability to walk through to education, employment and end-of-life care. Many of those involved with the charity are parents and it has always felt very much like a patient and parent focused, and led, organisation." James, Duchenne father

I didn't realise how much I need an outlet like that, it's the first time I've had the opportunity to openly talk about things. I try not to talk about it too much with friends and family as you have to filter what you say" Julia, Duchenne mother

1.4 Supporting young people transitioning to adulthood by providing professional-led residential and online skills training, helping them live a life that meets their aspirations and providing support to each other;

- 100% of young people felt more confident in themselves and what they can achieve after taking part in our 'Yes I Can' programme of the online sessions and the two residential weekends held in summer 2022.
- Brought 55 young people and adults together so they feel part of a supportive, dynamic community, no matter where they live. The most popular sessions included learning to drive, accessible travel and living independently.
- We work alongside colleagues, accessible residential activity centres and other partner organisations who also aim to provide education, care, support and independence training to young people with physical disabilities. We offer everybody living with Duchenne the support and training they need to transition to an independent adult life which matches their aspirations.

1.5 Support through end of life and bereavement by providing vital information for families and helping families retain their place in the Duchenne community, as a safe place to have these conversations.

- Support offered to 30+ families through end of life and bereavement.
- Online survey conducted in January 2023; 24 families engaged with survey posts and reached over 600 people.
- Working alongside with Child Bereavement UK, focusing on losing a child at any age.
- Created a new End of Life and Bereavement Support section of the website. Positive feedback received from families.

Testimonials from young people and adults

"I feel so much more content about living independently after this session." Alex, young adult living with Duchenne

"I wouldn't be in the position I am to help others who are living with Duchenne if it wasn't for talking to yourself, now I want to be that support for someone else who needs it" – Jamie, young adult living with Duchenne



1.6 Action Duchenne Annual International Conference 2022

November 2022 was our much anticipated first in-person conference since 2019. 270 registrants made it the largest Duchenne event in Europe, with 35 sessions delivered across 4 content streams over the 2 days. The conference brought together families, clinicians, therapists, researchers and pharmaceutical companies from across the world. Young people, adults and their families living with Duchenne were able to meet each other, gain empowering knowledge and discover how to live the very best life possible. For clinicians, researchers and academics, our conference provides an unrivalled opportunity to network, discuss the latest research findings and share expertise in optimal standards of care.

Testimonials from conference attendees



"It was such a well organized event. My husband and I can't thank Action Duchenne enough for organising this event. We would definitely be in a very different space mentally and emotionally had it not been for the excellent support you guys provide us. The opportunity to talk to the top minds in Duchenne world is something money can't buy and for that we are immensely grateful." Tanvi, Duchenne mother



"Both my wife and I have immensely enjoyed the Action Duchenne International Conference 2022 and would like to thank you and the charity for allowing it to happen. We have received a diagnosis of DMD for our son and are very much in the early stages of learning about this condition. This conference has been an immense help in our understanding of the condition, as well learning about current and future treatment options. Having met and listened to so many enthusiastic researchers about the work they are carrying out gives us much hope for the future." Chris, Duchenne father

"Congratulations on the Action Duchenne Conference!! Heard so many positive stories and it was great to see some posts featured on Twitter so it almost felt I was there. Hopefully next year I'll be able to attend again." Suzie-Ann, WDO





"It was great to meet you again at the conference, and finally have our first face-to-face conference since the pandemic - I am glad that I could contribute. I look forward to attending next year if I'm available."
Benjamin, Speaker and adult living with Duchenne

2. Funding research into potential therapeutic strategies for a future where lives are no longer limited by Duchenne and campaigns for optimal standards of care and accessibility of treatment.

2.1 Translarna

The Duchenne community celebrated a milestone moment in 2023 when NICE published their final guidance recommending Translarna (also called ataluren) as an option for treating Duchenne muscular dystrophy resulting from a 'nonsense mutation' in the dystrophin gene.

Action Duchenne has worked tirelessly alongside MDUK, families, clinicians and other patient groups in the continued fight for access to the treatment. We participated in a wide range of campaigning, policy and parliamentary activity that has all led up to this decision. Translarna has been available through a Managed Access Agreement (MAA) for the past six years and Action Duchenne and MDUK worked together as part of the Managed Access Oversight Group to represent the views of the Duchenne community.

Action Duchenne along with MDUK engaged closely with the final appraisal process and appeared at the two NICE committee meetings in September and December 2022 as patient experts. We are grateful to the many families who shared their experiences with us and allowed us to present these to the committee in our written and oral evidence. We are fully committed to our fight to make effective treatments available to everyone living with Duchenne muscular dystrophy.

2.2 Bone Health

Action Duchenne, in partnership with MDUK, is funding a research project lead by Jared Wong and the University of Glasgow. The aim is to develop national standards of care of management of osteoporosis and bone health in adults with Duchenne muscular dystrophy. There is currently no information on how we manage bone health in adults with DMD either in the recent Adult North Star guidance or the 2018 international standards of care (which only focussed on growing children). Through gathering a group of experts in the UK to develop national guidance on management of osteoporosis in adults with DMD, we hope to improve care for adults living with Duchenne both nationally and internationally. This research is crucial in addressing a critical gap in healthcare knowledge and ensuring a higher quality of life for individuals with Duchenne muscular dystrophy.

2.3 UK DMD Registry



We also continued our ongoing curation and support of the UK DMD registry as a part of our research strategy. The registry has more than 2,000 people registered including more than 1,000 people living with Duchenne and is governed by a Steering Committee chaired by Dr Michela Guglieri (Institute of Human Genetics, Newcastle University). The UK DMD Registry is designed to respond to pharmaceutical feasibility studies to help drug developers identify whether it is possible to run a clinical trial in the UK.

3. Striving for a more inclusive society, promoting the importance of human equality, day-to-day acceptance of disability and accessibility.

At Action Duchenne we are passionate about engaging with our stakeholders. In the past year we have conducted a number of surveys and interviews with our stakeholders to try and understand how our activities, from physiotherapy webinars to our community events and annual international conference, have created social impact for people living with Duchenne and their loved ones. As an organisation that is patient-led at its heart, we understand the importance of lived experience, human equality, day-to-day acceptance of disability and accessibility, and through our learning, sharing and networking process we have learnt the value of stakeholder engagement and the learning that comes from a deeper understanding and measurement of impact.

3.1 Living our strategic focus, creating shared value

We have a continued focus on the long-term future of the charity alongside the delivery of the vital services that we offer to the community. We have worked hard to open our community fundraising to a wider audience, increasing our support base as well as our platform within the charity landscape.



A highlight of our community fundraising for 2023 was a dinner dance organised by one of the families in our community. After their son Max was diagnosed with Duchenne in 2020, Ruth and Ian Taylor turned to Action Duchenne for support and began to turn their grief into positive action. Ruth, along with a committee made up of friends and family, organised a dinner dance with a live band, raffle and auction. Having worked hard to secure match funding from Santander, the event raised an incredible £54,528.58! We were truly inspired by Ruth and Ian's ability to use their sadness and grief to fuel an event filled with love, support and hope. The money raised alongside the awareness that the event generated will make a real, tangible difference to the lives of those affected by Duchenne muscular dystrophy both now and into the future, as well as realising the potential of widening our support base.

3.2 Building a strong team united by shared values

As the organisation has moved forward to ensure the delivery of our objectives around the community's needs and to fill the support gaps we have identified, our culture and ways of working have developed further. The recruitment of 2 new support officers has increased the capacity we have and the potential for increased development of our delivery.



The team here at Action Duchenne are currently working towards re-establishing our team of regular volunteers who use their time and expertise on a range of tasks, from website, HR support, impact measurement, webinars, writing blogs to researching fundraising opportunities. Currently we are excited to have begun to develop a community of contributors from within the groups we facilitate who are keen to share their invaluable lived experience. Going forward, using a robust framework designed to provide life-changing support for our community throughout their journey, we will continue to nurture and grow the culture at Action Duchenne to support our new strategy that puts the community first in everything we do.



3.3 Bringing our whole community together

Creating shared value with our partner organisations has always been fundamental to the way we deliver our work at Action Duchenne.

Over the last year, we have been proud to work together with all these amazing organisations and our community, right from the start, in supporting each project. We know we need to continue to improve how all those serving our community come together to provide what is most needed, and we are committed to working with other organisations to further a cohesive shared vision for Duchenne support. Action Duchenne is committed to the fight against the condition, and we are taking action - both to support research aimed at creating a future where lives are no longer limited by Duchenne and to provide tangible and much needed support to the community.



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Florence Boulton
National Director

The Trustees present their report and the financial statements for the twelve months ended 31 March 2023 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 2019).

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 Wellesley House, Duke of Wellington Avenue, Royal Arsenal, London SE18 6SS.

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:

Mark Silverman
Gary Fegan
Dr Tina Flatau (resigned on 26 September 2023)
Simon Dadd (resigned on 27 November 2023)
Roger Cockerton (Treasurer)
Nathalie Lion Haddad (appointed 22 March 2023, resigned 3 July 2023)
Victoria Penrice

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 Board would also like to thank all Patrons and Trustees, past and present, who have given their time and energy to Action Duchenne.

Introduction

In 2022/23 we continuously built up our financial viability while increasing the vital front-line support services we offer our community. We are putting everything into supporting our Duchenne children, young people, adults and their families, to help them gain empowering knowledge and discovering how to live the very best life possible.

Our 2021-2024 'Rebuild, Refocus and Reinvent' strategy plan provides a clear roadmap for our future strategy and marks the beginning of a new and exciting chapter. The year ahead looks busy and purposeful for Action Duchenne. We will continue:

- Building the capacity to deliver support to more individual and families – our success in securing funding from HM Government (in partnership with The National Lottery Community Fund) in 2022/23 has meant that we have been able to begin to deliver our much-needed 'All-through Support'.

- Focusing on delivering vital education and research project to a wider audience, increasing our support base as well as our platform within the charity landscape. Securing funding from trusts/foundations and corporate partners has meant that we have been able to begin to deliver our 'Supporting families through diagnosis and impossible decisions' project.

- Adapting and evolving our community fundraising activities and events – responding to the way supporters and donors like to support us, especially in our community context. We have started introducing more flexibility and options in the way support can be given, both in terms of methods of giving as well as engagement with more inclusive events.

- Steadily taking steps towards our ultimate goal of everybody living with Duchenne having the support they need and the respect they deserve. We believe, with the right encouragement, tools and positivity, children, young people, and adults living with Duchenne will create a bright future for themselves and be confident and happy enough to live that future to their full potential.

Action Duchenne is at the heart of the Duchenne community. We are proud to be collaborating with community leaders to address the unmet needs of the Duchenne community through designing programmes and services to maximise resources.

About us: our vision and objectives
Action Duchenne has a very clear vision: a world where lives are no longer limited by Duchenne muscular dystrophy.

We have three core objectives and are proud to spend 93.8p in every £1 raised on our charitable activities:

- Building a community by uniting and supporting families, educating about Duchenne, and raising the profile of the condition.

- Striving for a more inclusive society promoting the importance of human equality, day to day acceptance of disability and accessibility.

- Developing effective treatments for all by funding research, supporting clinical trials, and campaigning for access.

As science advances and more effective treatments are developing, the wider effects of Duchenne are changing and people are living for longer with the condition. With an increased need for support, we have identified opportunities to bring our "All-through-Support" to the entire community and this will be a major area of focus for Action Duchenne.

What is Duchenne?
Duchenne muscular dystrophy is a rare, disabling, muscle-wasting condition.

Young people are usually diagnosed around four years old and those living with the condition use a powered wheelchair in their teenage years and most will require a ventilator in their twenties.

Average life expectancy is said to be 30 years. There is no cure. However, with better technology, awareness, and improvement in the standards of care we are seeing people with Duchenne living for longer and more fulfilled lives.

Why Action Duchenne?

- **Committed:** staff, Trustees, Patrons, and ambassadors along with a supportive network of volunteers and partner organisations
- **Rigorous:** governance procedures, policies and processes are well controlled in line with regulatory frameworks and best practices
- **Collaborative:** working closely with Trustees, stakeholders, and national and international partner organisations to achieve goals
- **Innovative:** projects and programmes are created to satisfy an unmet need
- **Influential:** within the Duchenne community, pharmaceutical, health and social care sectors
- **Proactive:** forging partnerships with funders, organisations, corporates, and individuals to drive fundraising, revenue, and find new income streams
- **Reporting:** established systems to evaluate, report and feedback impact, communicating more effectively to all stakeholders

Financial review

In 2022/23 the Charity had a net surplus for the year of £131,019 following a surplus of £202,323 in the previous year. Scientific education, research, supporting families and grants payable increased by 101% from £252,927 to £508,861. Cost of events and general fundraising decreased by 53% from £75,320 to £35,725 which compounded the surplus for the year.

Income for the year totalled £711,864, this is an increase of 26% on the previous year (£562,186 in 2022), with amounts generated from donations and legacies decreasing 15% to £293,483 for the year (£347,160 in 2022), income from other trading activities, increasing 409% to £160,911for the year (£114,797 in 2022) and an increase 124% to £257,442 (£98,960 in 2022) in income from charitable activities.

Expenditure on charitable activities was £545,120 in the year (2022: £284,543), including allocated support costs. This represents 93.9% of total expenditure, compared to 79.1% in the previous year. As well as the research organisations listed above, this includes Eurordis membership, World Duchenne Organisation membership and Genetic Alliance UK membership.

Loan borrowings

During the year, the Charity repaid the Bounce Bank loan under the Coronavirus government-backed lending scheme in full.

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 of £145,200, 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 at the year-end are £480,195, up from £420,156 in March 2022; and restricted reserves are £71,220 (2022: £240). 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. Our research strategy sets out five areas, where we will focus our investment in research going forward:

- Innovation – we will co-fund novel research projects
- Outcome measures and natural history data
- Investing in tissue collection and biobanking
- Standards of Care – continuing our long-standing involvement in supporting the best possible multidisciplinary standards of care
- Maintaining the UK DMD Registry

The rapidly changing developments in international research demand a constant updating of the Charity's grant making policy. Our peer reviews grant applications as part of a two-stage review process and systematically reviews and agrees its research and grant making policy during the development of its annual business plan.

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.

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:

- 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 from the National Director and then the Finance Committee and/or the board of Trustees
- The management team prepare a business plan with internally audited yearly accounts and projections of budget expenditure at the end of each year. This is fully discussed by the Finance Committee and then at a specially convened meeting of the Board of Trustees
- The Finance Committee is responsible for overseeing the annual audit of the accounts by Simpson Wreford LLP
- Regular consideration by the Finance Committee and the board of financial results, variances from budgets, forecasts, and performance indicators
- Chain of command overseen by the Treasurer, 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
- Charity procedures (including financial control)
- Equality, diversity and inclusion
- Social media and digital/electronic communications

The Board of Trustees meet face to face or via remote conferencing at least four times a year. While the Charity aims to involve parents and those living with Duchenne muscular dystrophy as members of the Board of Trustees, a balance is sought by recruiting non-family members who have other scientific, business, and professional expertise. The Board is supported by four committees, each with specific terms of reference: corporate engagement, audit, finance & risk, delivery & research, and conference.

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:

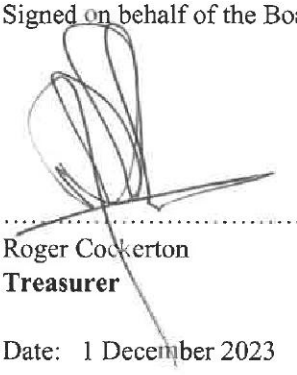
- there is no relevant audit information of which the charitable company's auditor is unaware; and
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

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.

Auditor
Simpson Wreford LLP were reappointed as Auditor 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.



.....
Roger Cockerton
Treasurer

Date: 1 December 2023

Opinion

We have audited the financial statements of Action Duchenne Limited (the 'Charitable company') for the year ended 31 March 2023 which comprise the Statement of Financial Activities, Statement of Financial Position, 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 March 2023 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 Companies Act 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.

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 Companies Act 2006 requires us to report to you if, in our opinion:

- adequate 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;
- we have not obtained all the information and explanations necessary for the purposes of our audit;
- the directors 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 directors' 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 page 10, the Trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as 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 Charitable company'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.

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 Act 2011 rather than the Companies Act 2006. Accordingly, 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 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 auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements. A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities]. This description forms part of our auditor's report.

Extent to which the audit was considered capable of detecting irregularities, including fraud

- the engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities, and skills to identify or recognise non-compliance with applicable laws and regulations;
- we identified the laws and regulations applicable to the Charitable company through discussions with directors and other management, and from our commercial knowledge and experience of membership organisations and support services sector;
- we focused on specific laws and regulations which we considered may have a direct material effect on the financial statements or the operations of the Charitable company, including the Companies Act 2006, data protection and Arts Council regulations;
- we assessed the extent of compliance with the laws and regulations identified above through making enquiries of management and inspecting legal correspondence; and
- identified laws and regulations were communicated within the audit team regularly and the team remained alert to instances of non-compliance throughout the audit.

Audit response to risks identified

We assessed the susceptibility of the Charitable company's financial statements to material misstatement, including obtaining an understanding of how fraud might occur, by:

- making enquiries of management as to where they considered there was susceptibility to fraud, their knowledge of actual, suspected, and alleged fraud; and
- considering the internal controls in place to mitigate risks of fraud and non-compliance with laws and regulations.

To address the risk of fraud through management bias and override of controls, we:

- performed analytical procedures to identify any unusual or unexpected relationships;
- tested journal entries to identify unusual transactions;
- assessed whether judgements and assumptions made in determining the accounting estimates were indicative of potential bias; and
- investigated the rationale behind significant or unusual transactions.

In response to the risk of irregularities and non-compliance with laws and regulations, we designed procedures which included, but were not limited to:

- agreeing financial statement disclosures to underlying supporting documentation and;
- enquiring of management as to actual and potential litigation and claims.
- reviewing correspondence with regulators.

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the directors and other management and the inspection of regulatory and legal correspondence, if any.

Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

Use of our report

This report is made solely to the Charitable company's members, as a body, in accordance with Chapter 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Charitable company's members 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 Charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Michael Broder, Senior Statutory Auditor

For and on behalf of Simpson Wreford LLP, Statutory Auditor

Wellesley House

Duke of Wellington Avenue

Royal Arsenal

London

SE18 6SS

Dated: 01/12/2023

Simpson Wreford LLP is eligible to act as an auditor in terms of 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 MARCH 2023

	Notes	2023 Unresticted funds	2023 Restricted funds	2023 Total funds	2022 Total funds
Income and endowments from:	4				
Donations and legacies		164,669	128,814	293,483	347,160
Charitable activities		-	257,442	257,442	98,960
Other trading activities		160,911	-	160,911	114,797
Investments		28	-	28	19
Other - Government grants		-	-	-	1,250
Total income		**325,608**	**386,256**	**711,864**	**562,186**
Expenditure on:	16				
Raising funds:					
Cost of events and general fundraising		35,725	-	35,725	75,320
Charitable activities:					
Campaigning and education,		40,528	87,680	128,208	79,040
Research, supporting families, and grants payable		153,057	227,596	380,653	173,887
Improved management and medical care		36,259	-	36,259	31,616
Total expenditure		**265,569**	**315,276**	**580,845**	**359,863**
Net income/(expenditure)		60,039	70,980	131,019	202,323
Transfers between funds		-	-	-	-
Net movement in funds		**60,039**	**70,980**	**131,019**	**202,323**
Reconciliation of funds:					
Balance at 1 April 2022		420,156	240	420,396	218,073
Balance at 31 March 2023		**480,195**	**71,220**	**551,415**	**420,396**

The notes on pages 19 to 29 form part of these financial statements.

ACTION DUCHENNE LIMITED

STATEMENT OF FINANCIAL POSITION
AS AT 31 MATCH 2023

	Notes	2023		2022	
		£	£	£	£
Fixed assets					
Tangible assets	5		2,161		2,881
Investments	6		2		2
			2,163		2,883
Current assets					
Debtors	7	6,948		11,049	
Cash at bank and in hand	20	625,039		475,928	
		631,987		486,977	
Current liabilities					
Creditors due within one year	8	(82,735)		(35,222)	
Net current assets			549,252		451,755
Total assets less current liabilities			551,415		454,638
Creditors due more than one year	9		-		(34,242)
Net assets	15		**551,415**		**420,396**
Represented by:					
Restricted funds	13		71,220		240
Unrestricted funds	14		480,195		420,156
			551,415		**420,396**

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the period ended 31 March 2023. 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.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

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 19 - 32 were approved by the Trustees on 1 December 2023 and signed on their behalf by:

.....

Roger Cockerton– **Trustee/Treasurer**

Registered charity number – 1101971
Registered charity – SC043852 (Scotland)

ACTION DUCHENNE LIMITED

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 31 MARCH 2023

	Notes	2023 Total £	2022 Total £
Cashflows from operating activities:			
Net cash provided by operating activities	**19**	194,066	88,454
Cashflows from investing activities:			
Dividends, interest, and rents from investments		28	19
Purchase of equipment		-	(2,772)
Proceeds from disposal of tangibles		-	-
Net cash (used in) by investing activites		28	(2,753)
Cashflows from financing activities:			
Loan received		-	-
Interest paid		(719)	(2,034)
Net cash (used in)/provided by financing activites		(44,264)	(4,486)
Change in cash and cash equivalents in the reporting period		149,111	79,181
Cash and cash equivalents as at 1 April 2022	**20**	475,928	396,747
Cash and cash equivalents as at 31 March 2023	**20**	**625,039**	**475,928**

1. Accounting policies

a) Company information – Action Duchenne Limited is a private company limited by guarantee, incorporated in England and Wales (Company Registration Number: 04899036) and registered as a charity with the Charities Commission (Registered Charity Number: 1101971) and in Scotland (Registered Charity Number – Scotland: SC043852). The principal and registered office is Wellesley House, Duke of Wellington Avenue, Royal Arsenal, London SE18 6SS.

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 2019) - (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 twelve months ended 31 March 2023 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 March 2023 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 17 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 auditors' fees.

1. Accounting policies (continued)

h) Programme related investments are included in the accounts at cost less amounts written off as grants payable.

i) Fixed assets are only capitalised were their values exceed £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) Redundancy payments – the Charity recognises redundancy payments relating to the early termination of an employee or group of employees immediately as an expense in the SOFA when there is a legal or constructive obligation to pay it.

1. Accounting policies (continued)

s) 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.

2. Employees

Costs to the company were as follows:

	2023 £	2022 £
Gross wages:		
- projects	242,636	187,551
- non-projects	26,615	18,169
Staff pension	5,847	7,013
Employer's NI contributions	19,901	14,826
	294,999	227,559

The defined contribution expense is allocated between restricted and unrestricted funds in accordance with the allocation of wages and salaries costs.

There was one employee at Action Duchenne Limited whose remuneration exceeded £60,000.

During the year redundancy payments totalling £nil (2022: £8,261) were made to employees.

The average number of full-time employees during the year was 9 (2022: 8) analysed as follows:

	2023 Number	2022 Number
Management - FTE	1.0	1.0
Research - FTE	1.0	1.0
Supporting families - FTE	5.5	4.0
Fundraising - FTE	1.2	1.2
Advocacy/Campaigns - FTE	0.3	0.8
	9.0	8.0

3. Net incoming resources is stated after charging

	2023 £	2022 £
Auditors' fees	7,800	6,500
Independent examination and accountancy fees	12,646	8,253
Depreciation	720	960

4. Analysis of income and endowments

	Unresticted funds £	Restricted funds £	2023 Total £	2022 Total £
Donations and legacies				
- Grants of a general nature	-	128,814	128,814	139,968
- Membership subscriptions	10,012	-	10,012	41,217
- Fundraising income	142,160	-	142,160	145,966
- Gift Aid	12,497	-	12,496	13,831
- Other	-	-	-	6,178
Charitable activities				
- Performance related grants	-	257,442	257,442	98,960
- Other	-	-	-	-
Other trading activities				
- Fundraising events	-	-	-	-
- Non-charitable trading activities	160,911	-	160,911	114,594
- Shop income	-	-	-	203
Investments	28	-	28	19
Other – Government grants	-	-	-	1,250
	325,608	386,256	711,864	562,186

5. Tangible assets

	Computer equipment £	Fixtures & fittings £	Office equipment £	Total £
Cost				
At 1 April 2022	2,772	-	1,425	4,197
Additions	-	-	-	-
Disposals	-	-	-	-
31 March 2023	2,772	-	1,425	4,197
Depreciation				
At 1 April 2022	693	-	623	1,316
Charge fpr the year	520	-	200	720
Disposals	-	-	-	-
At 31 March 2023	1,213	-	823	2036
Net book value				
At 31 March 2023	1,559	-	602	2,161
At 31 March 2022	2,079	-	802	2,881

6. Investments

	2023 £	2022 £
Programme related investments		
Convertible loan note in Halo Therapeutics LLC	225,000	225,000
Less: treated as grant paid 2012	(224,999)	(224,999)
	1	1

Halo Therapeutics is a clinical-stage biopharmaceutical firm focused on developing innovative therapies for rare fibrotic diseases such a 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.

There has been no communication from Halo Therapeutics regarding additional financing arrangements. The Trustees are therefore unable to consider the fair value of this holding and it should remain valued at cost.

	2023 £	2022 £
Other investments		
1,371 Ordinary shares of £0.001	1	1

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.

In December 2020 PepGen Limited participated in a $45m Series A funding round led by RA Capital Management with an exchange of shares originally denominated in Sterling to US Dollars in PepGen Inc.

In August 2021 PepGen Limited announced an IPO closing of $112.5m crossover financing to advance transformative therapies for neuromuscular diseases that resulted in an increase in our shareholding originally 1,371 to 13,467. The shares are listed on NASDAQ with a value of c$9 giving an overall value to our holding of $121,203. However, there is a restriction as to when shares can be sold.

In view of the high-risk nature of this type of investment the Board has decided not to recognise the value of this holding until a decision is reached whether to keep the shares once permitted to sell them.

7. Debtors

	2023 £	2022 £
Trade debtors	4,385	3,500
Other debtors	506	3,364
Prepayments	2,057	4,185
	6,948	11,049

8. Creditors: amounts falling due within one year

	2023 £	2022 £
Trade creditors	1,062	210
Accruals and deferred income	78,158	22,060
Bank loan	-	10,022
Other creditors	3,515	2,930
	82,735	166,090

Deferred income included above relates to donations totalling £nil (2022: £2,858), and grant income related to the following projects: Lottery All Through Support £nil (2022: £10,476); Jointly Supporting Newly Diagnosed £16,965 (2022: £nil); Corporate Sponsorships £35,000 (2022: nil). Donation income is deferred when it relates to a specific event taking place in the following period. Grant income is deferred in accordance with the grant documentation period.

9. Creditors : amounts falling due after more than one year

	2023 £	2022 £
Bank loans and overdrafts	-	34,242

10. Trustees' expenses and indemnity insurance

A Trustee may receive reimbursement of reasonable out-of-pocket expenses actually incurred in running the charity. In 2023, the total out-of-pocket expenses reimbursed was £392 (2022: £3) 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.

11. 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.

12. Other professional services provided by the auditor

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

13. Restricted funds

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

The movements for the year are as follows:

	At 1 April 2022	Incoming Resources	Outgoing Resources	Transfers	At 31 March 2023
	£	£	£	£	£
Restricted funds:					
National Lottery Fund	-	257,058	(227,596)	-	29,462
Supporting Families	240	47,300	(40,000)	-	7,540
Contact a Family	-	31,023	(15,885)	-	15,138
Transition to Adulthood	-	50,875	(31,795)	-	19,080
	240	**386,256**	**(315,276)**	-	71,220

Details of funds

National Lottery Fund – A grant of £480,130 was awarded from HM Government (in partnership with the National Lottery Community Fund) over two years to support the 'All-through Support' programme, the first of its type for the Duchenne community. The project was launched in October 2021. The aim is for every family receiving this life-changing diagnosis to be able to immediately access a support network and resources to help them at such a difficult time. The project is expected to be completed in 2023/24.

Supporting Families Through Diagnosis and Impossible Decisions (formerly known as Science on Tour) – supported by the Garfield Weston Foundation and a consortia of pharmaceutical companies. The second year of this project was completed in March 2023. Funding has been secured to support the delivery of the third year of activities in 2023/24.

Contact a Family – this project has helped to establish peer-to-peer support groups where Duchenne parents, grandparents, siblings, and those living with the condition come together to share experiences and support each other. These groups continue to thrive, topics being discussed are returning to school, anxiety, mobility decline and loneliness. These groups are vital and offer a safe space for our community. The project is part of the "All through Support" programme with funding secured for 2023/24.

14. Unrestricted funds

	General Fund £
At 1 April 2022	420,156
Income	325,608
Expenditure	(265,569)
Transfer	-
At 31 March 2023	**480,195**

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.

15. Analysis of net assets between funds

	Unrestricted funds £	Restricted funds £	2023 Total £	2022 Total £
Fixed assets	2,163	-	2,163	2,883
Current assets	543,802	88,185	631,987	486,977
Current liabilities	(65,770)	(16,965)	(82,735)	(35,222)
Non-current liabilities	-	-	-	(34,242)
	480,195	**71,220**	**551,415**	**420,396**

16. Analysis of resources expended

	2023 £	2022 £
Support costs:		
Bank charges and interest	4,226	4,847
Insurance	1,364	1,020
Wages and salaries	294,999	227,559
Printing, postage and stationery	6,282	7,251
Training, recruitment and other staff costs	35,523	23,687
Rent and rates	-	240
Computer costs	19,550	12,029
Storage	2,561	2,501
Telephone and internet costs	4,472	2,559
Depreciation	720	960
Loss on disposal of tangibles	-	851
Trustees' meetings	-	3
Governance costs	20,446	14,753
Professional fees	17,600	13,834
Miscellaneous expenditure	7,102	4,065
	414,845	316,159

Support and governance costs are allocated as follows:

	Support and governance £	Direct costs £	Total £
Research, supporting families, and grants payable 56%	234,761	145,891	380,653
Fundraising and events 6.75%	28,002	7,723	35,725
Scientific education 28%	116,903	11,305	128,208
Improved management and medical care 8%	35,179	1,080	36,259
	414,845	**165,999**	**580,845**

The allocation of support and governance costs has been determined on the basis of time spent by staff.

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:

	2023 £	2022 £
Grant – The University of Newcastle	-	21,426
Grant – Queen Mary University London	-	25,320
Grant – World Duchenne Organisation	-	-
	-	46,746

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

	2023 £	2022 £
Grant to The University of Glasgow	10,590	-
	10,590	-

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

	2023 Total £	2022 Total £
Net surplus/(deficit) for the reporting period	131,019	202,323
Adjustments for:		
Depreciation charges	720	960
Loss on disposal of tangibles	-	851
Interest payable	719	2,034
Grant income related to bounce back loan	-	(1,250)
Dividends, interest, and rents from investments	(28)	(19)
Increase / (decrease) in debtors	4,101	18,612
Increase / (decrease) in creditors	57,535	(135,057)
Net cash provided by (used in) operating activites	194,066	88,454

19. Analysis of cash and cash equivalents

	2023 £	2022 £
Cash in hand	625,039	475,928
	625,039	475,928

20. Loans and overdrafts

	2023 £	2022 £
Bank loans	-	44,264
Payable within one year	-	10,022
Payable after one year	-	34,242

The long-term bank loan is secured by fixed and negative charge over all the assets of the Charity.

21. Events after the reporting period

There are no events after the reporting date which require disclosure in the financial statements.

ACTION DUCHENNE LIMITED

England & Wales - Charity number 1101971

Accounts

Company number: 04899036

Registered charity number: 1101971

Registered charity number (Scotland): SC043852

AMENDED

ACTION DUCHENNE LIMITED

ANNUAL REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

ACTION DUCHENNE LIMITED

ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

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ADMINISTRATIVE AND STATUTORY DETAILS

Board of Trustees	Mark Silverman Gary Fegan Roger Cockerton (Treasurer) Dr Tina Flatau Simon Dadd Victoria Penrice
National Director	Florence Boulton
Scientific Advisory Board	Dame Professor K Davies – Chair Professor M Wood – Vice Chair
Registered office	Wellesley House Duke of Wellington Avenue Royal Arsenal London SE18 6SS
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 knows it will take a coordinated and sustained national and international effort to fulfil our vision: *a world where lives are no longer limited by Duchenne muscular dystrophy.*

Rebuild, refocus and reinvest

To achieve this mission and build the capacity for us to deliver support to more individuals and families, 2021-2022 has been a period of intensive change for Action Duchenne due to COVID pandemic. We have looked carefully at our goals and objectives and at our ways of working. That has involved us considering the capabilities that we need to provide the quality support that our community deserves. 2022 we have:



- looked at both the impact and effectiveness of the activities we carry out as well as their efficiency;
- focused on delivering meaningful and much-needed support, education and research projects as well as opening our community fundraising and events projects to a wider audience, increasing our support base as well as our platform within the charity landscape; and
- steadily built on this solid foundation, taking steps towards our ultimate goal of everybody living with Duchenne having the support they need and the respect they deserve.

Our success in securing funding from the National Lottery has meant that we have been able to begin to deliver our much-needed 'All-through Support' programme. The first programme of its type for the Duchenne community, has been designed to provide life-changing support for our community throughout their journey. We have supported over 1,000 vulnerable Duchenne young people, adults and their families. They have received direct help through our 'All-through Support' programme. We are proud to play our part in building a future where individuals do not feel isolated or marginalised; where the Duchenne community can come together, share experience and be part of an understanding and inclusive society.



As a result of the positive ripple effect of the 'All-through' approach, we are now more engaged with the needs of our community; better connected with other organisations in our area as we compliment and align services; and more confident about how and where Action Duchenne can uniquely act to make a difference. It has been a privilege for the team to learn from other partner organisations on every continent as we have worked on some of the most urgent needs and challenges faced in our community. We have been overwhelmed by kind words and advice from our families, supporters, Trustees, volunteers and partner organisations. We appreciate all the engaged, passionate and thoughtful support we have received.

We value each and every member of our Patrons, ambassadors and Trustees, volunteers and staff, and have truly benefited from their expertise, leadership, compassion, and generosity- we appreciate that you used all of your experience, skills, knowledge and education to move our charity forward. For their ability to see a better world. For being all that they are and doing all that they do.

All-through Support' programme

Our 'All-through Support' programme was launched in October 2021- we want every family receiving this life-changing diagnosis to be able to immediately access our support network and resources to help them at such a difficult time. Securing funding from HM Government (in partnership with The National Lottery Community Fund, Garfield Weston Foundation and a consortium of corporate partners has meant that we have been able to begin to deliver our vital 'All-through Support' programme. In 2021-22 our work included:



- made contact with the North Star network to gain an understanding of Duchenne and the diagnostic pathway.
-11 peer-to-peer support groups have been established. Support materials have been produced, and shared with the hospitals identified.



- planned 23 in-person 'Science on Tour' workshops across the UK , showcasing interactive scientific exhibits depicting the different stages of Duchenne, helping families understand prevalence, progression and treatments available.
- 390 families have signed up and received bespoke 1:1 support with 118 attendees to date, of which 68 are new contacts have been made.

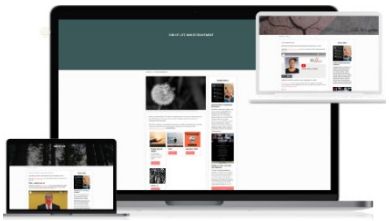
'Supporting parents through diagnosis'



- supported 650 young people, adults and their families through our direct and bespoke support calls, video chats and messaging, and online and in person meetings.
- established 14 peer-to-peer new support groups, hosted 21 group support meetings, and created a new supporting schools webpage with resources for schools and parents.



- planned 12 professional-led skills training to provide social interaction, skills training and peer-to-peer support.
- 45 individuals have signed up for their transition to adulthood project. Planned two residential led weekends booked at an accessible adventure centre.



- contacts have been made with Child Bereavement UK who have agreement to signpost to each other and permission for both charities to link written materials.
- produced support materials, and shared with other partner organisations.

International Conference 2021

The 2021 Action Duchenne International Conference brought together families, clinicians, therapists, researchers and pharmaceutical companies from across the world. Young people, adults and their families living with Duchenne were able to meet each other, gained empowering knowledge and discovered how to live the very best life possible. For clinicians, researchers and academics, our conference provided an unrivalled opportunity to network, discuss the latest research findings and shared expertise in optimal standards of care.



Highlights from our conference in 2021:

- 40+ nations represented
- 50+ expert speakers from around the world
- 460+ registrations with 4,000+ page-views over the conference weekend
- 22 Duchenne patient organisations represented.

Supporting research

In 2021-22 our work included:

-completed a multi-year Clinical Trials Lectureship project at Newcastle University which we funded alongside other Duchenne charities. The Clinical Trials Lectureship grant enabled Dr Michela Guglieri to serve as the Clinical Research Team Leader within the John Walton Muscular Dystrophy Research Centre in Newcastle; a key role in one of the UK's biggest Duchenne muscular dystrophy (DMD) research centres, that ensures trials are run smoothly, safely, and generate high quality data;

-completed our research project in Dr Yung-Yao Lin's laboratory at Queen Mary University of London. The researchers combined stem cell and gene editing technology, to make a system that allows them to study the junction between nerve and muscle cells in Duchenne, in the laboratory. The system can also test the potential effectiveness of drugs that target this pathway and researchers have already identified one interesting type of potential drug. Together with Barts Charity, we are proud to support this innovative project that aims to develop techniques to combine stem cell and gene-editing technologies in Duchenne; and





-continued our ongoing curation and support of the UK DMD registry as a key part of our research strategy. The registry has more than 2,000 people registered including more than 1,000 people living with Duchenne and is governed by a Steering Committee chaired by Dr Michela Guglieri (Institute of Human Genetics, Newcastle University). The UK DMD Registry is designed to respond to pharmaceutical feasibility studies to help drug developers identify whether it is possible to run a clinical trial in the UK.

Living our strategic focus, creating shared value

The recent period we have all experienced has been challenging and unprecedented across the globe. There has been a huge impact on the charity landscape. Our priority in 2021-22 was navigating the disruption caused by COVID and riding out the fundraising difficulties that all charities faced during that time.



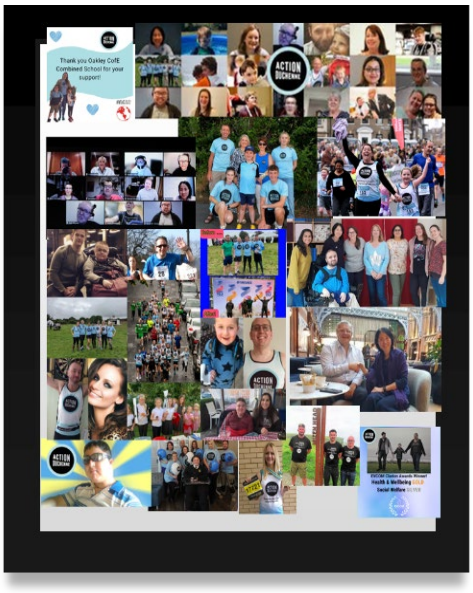
Action Duchenne is now focusing on opening our community fundraising to a wider audience, increasing our support base as well as our profile within the charity landscape. Our work relies on voluntary donations from individuals, groups and companies. It is your support that enables us to do what we do.

As well as this, we stayed focused on the long-term future of the charity and we realigned our strategy with all the complexities and challenges entailed in that. We have made huge strides in the last 12 months, further securing the financial viability of the charity while increasing the vital services we offer our community.

Building a strong team united by shared values

This year has been a period of significant change within the team at Action Duchenne. As the organisation has moved forward to realign our objectives around the community's needs and to fill the support gaps we have identified, our culture and we have adapted our ways of working to enable us to deliver. With new funding in place the charity has turned a new chapter.

2021-2022 saw Action Duchenne reset and restructure, bringing in new ideas, new projects and research. It has been great to receive positive feedback from families and supporters - securing funding support from a number of corporates, trusts and foundations who recognised the power of our supporting families work and wished to help us to deliver.



The team here at Action Duchenne had the pleasure of working with 25 (2020-21: 18) regular volunteers giving their time and expertise on a range of tasks, from website, HR support, impact measurement, webinars, writing blogs to researching fundraising opportunities. They have been brought together, to help to secure our financial viability and to initiate crucial support services for our community. Using a robust framework designed to provide life-changing support for our community throughout their journey, we will continue to nurture and grow the culture at Action Duchenne to support our new strategy that puts the community first in everything we do.

Bringing our whole community together

Action Duchenne is the longest serving Duchenne-only charity in the United Kingdom, providing a vital support mechanism for young people, adults and their families at every stage of their Duchenne journey. Creating shared value with our partner organisations has always been fundamental to the way we deliver our work at Action Duchenne. We believe that our charity can only be successful in the long term by creating value for both partner organisations and the community, putting people in the lead so they can help to define and refine our work and our role.



Over the last year, we have been proud to work together with all these amazing organisations and our community, right from the start, in supporting each project. We know we need to continue to improve how all those serving our community come together to provide what is most needed, and we are committed to working with other organisations to further a cohesive shared vision for Duchenne support. Action Duchenne is committed to the fight against the condition and we are taking action - both to support research aimed at creating a future where lives are no longer limited by Duchenne and to provide tangible and much needed support to the community.

Duchenne muscular dystrophy is a rare genetic condition caused by mutations in the dystrophin gene, which prevents 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. Duchenne is usually diagnosed around the age of 4, and people living with the condition experience progressive muscle weakness. They typically need to use a powered wheelchair from their early teens, and since the heart and breathing muscles are affected most will require a ventilator in their twenties. Life expectancy is around 30 years. There is no cure. However, with better technology, awareness and improvement in the standard of care we are seeing people with Duchenne living for longer and more fulfilled lives.

……

Florence Boulton
National Director

The Trustees present their report and the financial statements for the twelve months ended 31 March 2022 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 2019).

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 Wellesley House, Duke of Wellington Avenue, Royal Arsenal, London SE18 6SS.

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:

Mark Silverman
Gary Fegan
Dr Tina Flatau
Robert Laid – resigned 14/06/2022
Simon Dadd
Roger Cockerton (Treasurer)
Victoria Penrice
Ellen Lambrix – resigned 31/7/2022

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 also like to thank all Patrons and Trustees, past and present, who have given their time and energy to Action Duchenne.

Introduction

In 2021/22 we turned our charity around. We dramatically built up our financial viability while increasing the vital services we offer our community. For the past two years, COVID-19 has meant that our supporting families work has taken place virtually. We have worked tirelessly throughout the pandemic to provide front-line support to our community. The team here at Action Duchenne are putting everything into supporting our Duchenne children, young people, adults and their families, to help them gain empowering knowledge and discovering how to live the very best life possible.

Our 2021-2024 'Rebuild, Refocus and Reinvent' strategy plan provides a clear roadmap for our future strategy and marks the beginning of a new and exciting chapter. The year ahead looks busy and purposeful for Action Duchenne. We will continue:

- Building the capacity to deliver support to more individual and families – our success in securing funding from HM Government (in partnership with The National Lottery community Fund) in 2021/22 has meant that we have been able to begin to deliver our much-needed 'All-through Support'.
- Focusing on delivering vital education and research project to a wider audience, increasing our support base as well as our platform within the charity landscape. Securing funding from trusts/foundations and corporate partners has meant that we have been able to begin to deliver our 'Supporting families through diagnosis and impossible decisions' project.
- Adapting and evolving our community fundraising activities and events – responding to the way supporters and donors like to support us, especially in our community context. We have started introducing more flexibility and options in the way support can be given, both in terms of methods of giving as well as engagement with more inclusive events.
- Steadily taking steps towards our ultimate goal of everybody living with Duchenne having the support they need and the respect they deserve. We believe, with the right encouragement, tools and positivity, children, young people and adults living with Duchenne will create a bright future for themselves and be confident and happy enough to live that future to their full potential.

Action Duchenne is at the heart of the Duchenne community. We are proud to be collaborating with community leaders to address the unmet needs of the Duchenne community through designing programmes and services to maximise resources.

About us: our vision and objectives

Action Duchenne has a very clear vision: a world where lives are no longer limited by Duchenne muscular dystrophy.

We have three core objectives and are proud to spend 79.1p in every £1 raised on our charitable activities:

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

While we hope that research and clinical trials will one day lead to a treatment, or cure, for Duchenne, we believe it is vital to support families living with the condition today. We support families from diagnosis through their whole Duchenne journey.

What is Duchenne?

Duchenne muscular dystrophy is a rare, disabling, muscle-wasting condition.

Young people are usually diagnosed around four years old and those living with the condition use a powered wheelchair in their teenage years and most will require a ventilator in their twenties.

Average life expectancy is said to be 30 years. There is no cure. However, with better technology, awareness and improvement in the standards of care we are seeing people with Duchenne living for longer and more fulfilled lives.

Why Action Duchenne?

- **Committed:** staff, Trustees, Patrons and ambassadors along with a supportive network of volunteers and partner organisations
- **Rigorous:** governance procedures, policies and processes are well controlled in line with regulatory frameworks and best practices
- **Collaborative:** working closely with Trustees, stakeholders, and national and international partner organisations to achieve goals
- **Innovative:** projects and programmes are created to satisfy an unmet need
- **Influential:** within the Duchenne community, pharmaceutical, health and social care sectors
- **Proactive:** forging partnerships with funders, organisations, corporates, and individuals to drive fundraising, revenue, and find new income streams
- **Reporting:** established systems to evaluate, report and feedback impact, communicating more effectively to all stakeholders

Our reflection

Action Duchenne is at the heart of the Duchenne community. 50% of our staff and Trustees have a child living with the condition and this provides real, on-the-spot expertise on what the families we support need and the situations they face. We have had some major successes. We brought together the group of scientists who developed the 'exon skipping' drugs that offer hope for some living with Duchenne; our disease registry has put the UK at the forefront of clinical trials; our research funding has given more than 130 people the chance to take part in a clinical trial.

Our support team talks to over 2,000 families living with Duchenne every year. We help families to apply for benefits, attend meetings at schools alongside families or simply listen as families talk about their child's condition. Our work provides a vital lifeline to families, and we aim to help every single person and family affected by the condition. Following diagnosis, parents often say "the only person who understands what I'm going through is another Duchenne parent".

The team works hard to bring families together, to support each other. We organise the largest Duchenne conference in Europe, bringing families from across the UK together with expert clinicians, researchers, and drug developers. We work with others wherever possible and have acted as a springboard for other patient groups.

Financial review

In 2021/22 the Charity had a net surplus for the year of £202,323 following a surplus of £105,045 in the previous year. The year has been characterised by a challenging environment across the charity sector, we were fortunate enough to see an increase in donations and legacies. Scientific education, research and grants payable decreased by 15.5% from £299,403 to £252,927 which compounded the surplus for the year.

Income was £562,186 in 2021/22 and £472,906 (restated) in 2020/21, with amounts generated from donations and legacies increasing 55.8%, income from other trading activities, decreasing 10.9% and a decrease in income from charitable activities of 5% due to the COVID pandemic.

Expenditure on charitable activities was £284,543 in the year (2021: £326,138), including allocated support costs. This represents 79.1% of total expenditure, compared to 88.7% in the previous year. Of this, £284,543 was spent on charitable activities (2021: £326,138). As well as the research organisations listed above, this includes Eurordis membership, World Duchenne Organisation membership and Genetic Alliance UK membership.

Operational costs continue to be managed tightly, and the National Director has initiated a focused programme of work to correct the fall in charitable income in particular.

Loan borrowings
During the prior year, the Charity secured a £50,000 Bounce Bank loan under the Coronavirus government-backed lending scheme. This was interest free for 12 months and no repayments were due during this period. Repayments began from September 2021. In the current year repayments totalling £6,520 were made which included £785 of interest.

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 of £92,000, 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 at the end of March 2022 are £420,156, up from £218,073 in March 2021; and restricted reserves are £240 (2021: £Nil - restated). 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. Our research strategy sets out five key areas, where we will focus our investment in research going forward:

- Innovation – we will co-fund novel research projects
- Outcome measures and natural history data
- Investing in tissue collection and biobanking
- Standards of Care – continuing our long-standing involvement in supporting the best possible multidisciplinary standards of care
- Maintaining the UK DMD Registry

The rapidly changing developments in international research demand a constant updating of the Charity's grant making policy. Our peer reviews grant applications as part of a two-stage review process and systematically reviews and agrees its research and grant making policy during the development of its annual business plan.

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.

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:

- 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 from the National Director and then the Finance Committee and/or the board of Trustees
- The management team prepare a business plan with internally audited yearly accounts and projections of budget expenditure at the end of each year. This is fully discussed by the Finance Committee and then at a specially convened meeting of the Board of Trustees
- The Finance Committee is responsible for overseeing the annual audit of the accounts by Simpson Wreford LLP
- Regular consideration by the Finance Committee and the board of financial results, variances from budgets, forecasts, and performance indicators
- Chain of command overseen by the Treasurer, 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
    - HR
    - Safeguarding
    - Trustee and volunteer roles and responsibilities
    - Charity procedures (including financial control)
    - Equal opportunities
    - Social media and digital/electronic communications

The Board of Trustees meet face to face or via remote conferencing at least four times a year. While the Charity aims to involve parents and those living with Duchenne muscular dystrophy as members of the Board of Trustees, a balance is sought by recruiting non-family members who have other scientific, business, and professional expertise. The Board is supported by four committees, each with specific terms of reference: corporate engagement, audit, finance & risk, delivery & research, and conference.

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.

Auditor
Simpson Wreford LLP were reappointed as Auditor 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.

……
Roger Cockerton
Treasurer

Date: 8 December 2022

Opinion

We have audited the financial statements of Action Duchenne Limited (the 'Charitable company') for the year ended 31 March 2022 which comprise the Statement of Financial Activities, Statement of Financial Position, 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 March 2022 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 Companies Act 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.

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 Companies Act 2006 requires us to report to you if, in our opinion:

- adequate 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;
- we have not obtained all the information and explanations necessary for the purposes of our audit;
- the directors 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 directors' 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 page 10, the Trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as 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 Charitable company'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.

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 Act 2011 rather than the Companies Act 2006. Accordingly, 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 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 auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements. A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities]. This description forms part of our auditor's report.

Extent to which the audit was considered capable of detecting irregularities, including fraud

- the engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities and skills to identify or recognise non-compliance with applicable laws and regulations;
- we identified the laws and regulations applicable to the Charitable company through discussions with directors and other management, and from our commercial knowledge and experience of membership organisations and support services sector;
- we focused on specific laws and regulations which we considered may have a direct material effect on the financial statements or the operations of the Charitable company, including the Companies Act 2006, data protection and Arts Council regulations;
- we assessed the extent of compliance with the laws and regulations identified above through making enquiries of management and inspecting legal correspondence; and
- identified laws and regulations were communicated within the audit team regularly and the team remained alert to instances of non-compliance throughout the audit.

Audit response to risks identified

We assessed the susceptibility of the Charitable company's financial statements to material misstatement, including obtaining an understanding of how fraud might occur, by:

- making enquiries of management as to where they considered there was susceptibility to fraud, their knowledge of actual, suspected and alleged fraud; and
- considering the internal controls in place to mitigate risks of fraud and non-compliance with laws and regulations.

To address the risk of fraud through management bias and override of controls, we:

- performed analytical procedures to identify any unusual or unexpected relationships;
- tested journal entries to identify unusual transactions;
- assessed whether judgements and assumptions made in determining the accounting estimates were indicative of potential bias; and
- investigated the rationale behind significant or unusual transactions.

In response to the risk of irregularities and non-compliance with laws and regulations, we designed procedures which included, but were not limited to:

- agreeing financial statement disclosures to underlying supporting documentation and;
- enquiring of management as to actual and potential litigation and claims.
- reviewing correspondence with regulators.

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the directors and other management and the inspection of regulatory and legal correspondence, if any.

Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

Use of our report

This report is made solely to the Charitable company's members, as a body, in accordance with Chapter 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Charitable company's members 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 Charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Michael Broder, Senior Statutory Auditor

For and on behalf of Simpson Wreford LLP, Statutory Auditor

Wellesley House

Duke of Wellington Avenue

Royal Arsenal

London

SE18 6SS

Dated: 8 December 2022

Simpson Wreford LLP is eligible to act as an auditor in terms of 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 MARCH 2022

	Notes	2022 Unresticted funds	2022 Restricted funds	2022 Total funds	2021 Total funds Restated
Income and endowments from:	**4**				
Donations and legacies		207,192	139,968	347,160	222,844
Charitable activities		3,534	95,426	98,960	104,128
Other trading activities		114,797	-	114,797	128,874
Investments		19	-	19	32
Other - Government grants		1,250	-	1,250	17,028
Total income		**326,792**	**235,394**	**562,186**	**472,906**
Expenditure on:	**17**				
Raising funds:					
Cost of events and general fundraising		75,320	-	75,320	41,723
Charitable activities:					
Scientific education		15,671	63,369	79,040	16,041
Research, supporting families, and grants payable		2,471	171,416	173,887	299,403
Improved management and medical care		31,616	-	31,616	10,694
Total expenditure		**125,078**	**234,785**	**359,863**	**367,861**
Net income/(expenditure)		201,714	609	202,323	105,045
Transfers between funds		369	(369)	-	-
Net movement in funds		**202,083**	**240**	**202,323**	**105,045**
Reconciliation of funds:					
Balance at 1 April 2021		218,073	-	218,073	113,028
Balance at 31 March 2022		**420,156**	**240**	**420,396**	**218,073**

The notes on pages 19 to 29 form part of these financial statements.

STATEMENT OF FINANCIAL POSITION
AS AT 31 MATCH 2022

	Notes	2022		2021 Restated	
		£	£	£	£
Fixed assets					
Tangible assets	**5**		2,881		1,920
Investments	**6**		2		2
			2,883		1,922
Current assets					
Debtors	**7**	11,049		29,661	
Cash at bank and in hand		475,928		396,747	
		486,977		426,408	
Current liabilities					
Creditors due within one year	**8**	(35,222)		(166,090)	
Net current assets			451,755		260,318
Total assets less current liabilities			454,638		262,240
Creditors due more than one year	**9**		(34,242)		(44,167)
Net assets	**15**		420,396		218,073
Represented by:					
Restricted funds	**13**		240		-
Unrestricted funds	**14**		420,156		218,073
			420,396		218,073

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the period ended 31 March 2022. 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.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

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 16 - 29 were approved by the Trustees on 8 December 2022 and signed on their behalf by:

……
Roger Cockerton– **Trustee/Treasurer**

Registered charity number – 1101971
Registered charity – SC043852 (Scotland)

ACTION DUCHENNE LIMITED

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 31 MARCH 2022

	Notes	2022 Total £	2021 Total £
Cashflows from operating activities:			
Net cash provided by operating activities	**19**	88,454	249,765
Cashflows from investing activities:			
Dividends, interest, and rents from investments		19	33
Purchase of equipment		(2,772)	(1,425)
Proceeds from disposal of tangibles		-	-
Net cash (used in) by investing activites		(2,753)	(1,392)
Cashflows from financing activities:			
Loan received		-	50,000
Loan repayment		(6,520)	-
Net cash (used in)/provided by financing activites		(6,520)	50,000
Change in cash and cash equivalents in the reporting period		79,181	298,373
Cash and cash equivalents as at 1 April 2021	**20**	396,747	98,374
Cash and cash equivalents as at 31 March 2022	**20**	**475,928**	**396,747**

1. Accounting policies

a) Company information – Action Duchenne Limited is a private company limited by guarantee, incorporated in England and Wales (Company Registration Number: 04899036) and registered as a charity with the Charities Commission (Registered Charity Number: 1101971) and in Scotland (Registered Charity Number – Scotland: SC043852). The principal and registered office is Wellesley House, Duke of Wellington Avenue, Royal Arsenal, London SE18 6SS.

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 2019) - (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 twelve months ended 31 March 2022 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 March 2022 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 17 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 auditors' fees.

1. Accounting policies (continued)

h) Programme related investments are included in the accounts at cost less amounts written off as grants payable.

i) Fixed assets are only capitalised were 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) Redundancy payments – the Charity recognises redundancy payments relating to the early termination of an employee or group of employees immediately as an expense in the SOFA when there is a legal or constructive obligation to pay it.

1. Accounting policies (continued)

s) 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.

2. Employees

Costs to the company were as follows:

	2022 £	2021 £
Gross wages:		
- projects	187,551	169,635
- non-projects	18,169	20,498
Staff pension	7,013	4,123
Employer's NI contributions	14,826	14,315
	227,559	208,571

The defined contribution expense is allocated between restricted and unrestricted funds in accordance with the allocation of wages and salaries costs.

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

During the year redundancy payments totalling £8,261 (2021: £Nil) were made to employees.

The average number of full-time employees during the year was 8 (2021: 6) analysed as follows:

	2022 Number	2021 Number
Management - FTE	1.0	0.6
Research - FTE	1.0	0.6
Supporting families - FTE	4.0	2.3
Fundraising - FTE	1.2	1.8
Advocacy/Campaigns - FTE	0.8	0.7
	8.0	6.0

3. Net incoming resources is stated after charging

	2022 £	2021 £
Auditors' fees	6,500	-
Independent examination and accountancy fees	8,253	7,620
Depreciation	960	640

4. Analysis of income and endowments

	Unresticted funds £	Restricted funds £	2022 Total £	2021 Total - Restated £
Donations and legacies				
- Grants of a general nature	-	139,968	139,968	18,551
- Membership subscriptions	41,217	-	41,217	41,711
- Fundraising income	145,966	-	145,966	104,688
- Gift Aid	13,831	-	13,831	7,894
- Other	6,178	-	6,178	50,000
Charitable activities				
- Performance related grants	3,534	95,426	98,960	104,128
- Other	-	-	-	-
Other trading activities				
- Fundraising events	-	-	-	4,375
- Non-charitable trading activities	114,594	-	114,594	123,066
- Shop income	203	-	203	1,433
Investments	19	-	19	32
Other – Government grants	1,250	-	1,250	17,028
	326,792	235,394	562,186	472,906

5. Tangible assets

	Computer equipment £	Fixtures & fittings £	Office equipment £	Total £
Cost				
At 1 April 2021	25,147	1,098	8,264	34,509
Additions	2,772	-	-	2,772
Disposals	(25,147)	(1,098)	(6,839)	(33,084)
31 March 2022	2,772	-	1,425	4,197
Depreciation				
At 1 April 2021	24,407	1,087	7,095	32,589
Charge fpr the year	693	-	267	960
Disposals	(24,407)	(1,087)	(6,739)	(32,233)
At 31 March 2022	693	-	623	1,316
Net book value				
At 31 March 2022	2,079	-	802	2,881
At 31 March 2021	740	11	1,169	1,920

6. Investments

	2022 £	2021 £
Programme related investments		
Convertible loan note in Halo Therapeutics LLC	225,000	225,000
Less: treated as grant paid 2012	(224,999)	(224,999)
	1	1

Halo Therapeutics is a clinical-stage biopharmaceutical firm focused on developing innovative therapies for rare fibrotic diseases such a 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.

There has been no communication from Halo Therapeutics regarding additional financing arrangements. The Trustees are therefore unable to consider the fair value of this holding and it should remain valued at cost.

	2022 £	2021 £
Other investments		
1,371 Ordinary shares of £0.001	1	1

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.

In December 2020 PepGen Limited participated in a $45m Series A funding round led by RA Capital Management with an exchange of shares originally denominated in Sterling to US Dollars in PepGen Inc.

In August 2021 PepGen Limited announced an IPO closing of $112.5m crossover financing to advance transformative therapies for neuromuscular diseases that resulted in an increase in our shareholding originally 1,371 to 13,467. The shares are listed on NASDAQ with a value of c$9 giving an overall value to our holding of $121,203. However, there is a restriction as to when shares can be sold.

In view of the high-risk nature of this type of investment the Board has decided not to recognise the value of this holding until a decision is reached whether to keep the shares once permitted to sell them.

7. Debtors

	2022	2021 Restated
	£	£
Trade debtors	3,500	21,426
Other debtors	3,364	4,441
Prepayments	4,185	3,794
	11,049	29,661

8. Creditors: amounts falling due within one year

	2022	2021
	£	£
Trade creditors	210	21,426
Accruals and deferred income	22,060	137,426
Bank loan	10,022	5,833
Other creditors	2,930	1,405
	35,222	166,090

Deferred income included above relates to donations totalling £2,858 (2021: £Nil), and grant income related to the following projects: Lottery All Through Support £10,476 (2021: £Nil); Supporting Families (formerly Science on Tour) £Nil (2021: £90,000); and Demelza project sponsorship of £Nil (2021: £15,000). Donation income is deferred when it relates to a specific event taking place in the following period. Grant income is deferred until the Charity incurs eligible expenditure on the project.

9. Creditors : amounts falling due after more than one year

	2022	2021
	£	£
Bank loans and overdrafts	34,242	44,167

10. Trustees' expenses and indemnity insurance

A Trustee may receive reimbursement of reasonable out-of-pocket expenses actually incurred in running the charity. In 2022, the total out-of-pocket expenses reimbursed was £3 to one Trustee (2021: £Nil) 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.

11. 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.

12. Other professional services provided by the auditor

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

13. Restricted funds

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

The movements for the year are as follows:

	At 1 April 2021 - Restated	Incoming Resources	Outgoing Resources	Transfers	At 31 March 2022
	£	£	£	£	£
Restricted funds:					
National Lottery Fund	-	95,426	(95,426)	-	-
Supporting Families	-	115,000	(114,760)	-	240
Contact a Family	-	9,968	(9,968)	-	-
Demelza	-	15,000	(14,631)	(369)	-
	-	235,394	(234,785)	(369)	240

Details of funds

National Lottery Fund – A grant of £480,130 was awarded from HM Government (in partnership with the National Lottery Community Fund) over two years to support the 'All-through Support' programme, the first of its type for the Duchenne community. The project was launched in October 2021. The aim is for every family receiving this life-changing diagnosis to be able to immediately access a support network and resources to help them at such a difficult time. The project is expected to be completed in 2023/24.

Supporting Families Through Diagnosis and Impossible Decisions (formerly known as Science on Tour) – supported by the Garfield Weston Foundation and a consortia of pharmaceutical companies. The first year of this project was completed in March 2022. Funding has been secured to support the delivery of the second year of activities in 2022/23.

Contact a Family – this project has helped to establish peer-to-peer support groups where Duchenne parents, grandparents, siblings and those living with the condition come together to share experiences and support each other. These groups continue to thrive, topics being discussed are returning to school, anxiety, mobility decline and loneliness. These groups are vital and offer a safe space for our community. The project was completed in January 2022.

Demelza – this project has developed joint working between Demelza House Children's Hospice and Action Duchenne to support young people and their families. Reviews to be carried out to collect information and data to help decide how to improve the support for young people living with Duchenne and their families who are going through the transition process. The project was completed in November 2021.

14. Unrestricted funds

	General Fund £
At 1 April 2021 - Restated	218,073
Income	326,792
Expenditure	(125,078)
Transfer	369
At 31 March 2022	420,156

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.

15. Analysis of net assets between funds

	Unrestricted funds £	Restricted funds £	2022 Total £	2021 Total £
Fixed assets	2,883	-	2,883	1,922
Current assets	476,261	10,716	486,977	426,408
Current liabilities	(24,746)	(10,476)	(35,222)	(166,090)
Non-current liabilities	(34,242)	-	(34,242)	(44,167)
	420,156	240	420,396	218,073

16. Fund Transfers

In the prior year, there was a transfer of £420 from unrestricted funds to the Demelza restricted fund. This was due to a timing difference between set up-costs and the quarterly allocation of incoming resources. As a result, in the current year there was a balance of £369 remaining on the Demelza fund and as such a transfer has been made from restricted funds back to unrestricted funds. This equates to a net overspend of £51 on the Demelza project.

17. Analysis of resources expended

	2022 £	2021 £
Support costs:		
Bank charges and interest	4,847	1,216
Insurance	1,020	1,612
Wages and salaries	227,559	208,571
Printing, postage and stationery	7,251	7,380
Training, recruitment and other staff costs	23,687	3,371
Rent and rates	240	6,026
Computer costs	12,029	10,403
Storage	2,501	2,201
Telephone and internet costs	2,559	2,292
Depreciation	960	640
Loss on disposal of tangibles	851	-
Trustees' meetings	3	-
Governance costs	14,753	15,650
Professional fees	13,834	6,188
Miscellaneous expenditure	4,065	1,800
	316,159	267,350

Grants totalling £46,746 were payable to 3 medical research institutions, as described in note 18. These were accrued in the prior year financial statements.

Support and governance costs are allocated as follows:

	Support and governance £	Direct costs £	Total £
Research, supporting families, and grants payable 55%	173,887	-	173,887
Fundraising and events 10%	31,616	43,704	75,320
Scientific education 25%	79,040	-	79,040
Improved management and medical care 10%	31,616	-	31,616
	316,159	43,704	359,863

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

18. 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:

	2022 £	2021 £
Grant – The University of Newcastle	21,426	50,000
Grant – Queen Mary University London	25,320	-
Grant – World Duchenne Organisation	-	912
	46,746	50,912

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

	2022 £	2021 £
Grant to The Univerisity of Newcastle	-	21,426
Grant to Queen Mary University London	-	25,320
	-	46,746

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

	2022 Total £	2021 Total £
Net surplus/(deficit) for the reporting period	202,323	105,045
Adjustments for:		
Depreciation charges	960	640
Loss on disposal of tangibles	851	-
Interest payable	2,034	-
Grant income related to bounce back loan	(1,250)	-
Dividends, interest and rents from investments	(19)	(33)
(Increase) / decrease in debtors	18,612	14,206
Increase / (decrease) in creditors	(135,057)	129,907
Net cash provided by (used in) operating activites	88,454	249,765

20. Analysis of cash and cash equivalents

	2022 £	2021 £
Cash in hand	475,928	396,747
	475,928	396,747

21. Commitments under operating leases

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

	2022 £	2021 £
Operating leases which expire: within two to five years	-	-

22. Loans and overdrafts

	2022 £	2021 £
Bank loans	44,264	50,000
Payable within one year	10,022	5,833
Payable after one year	34,242	44,167

The long-term bank loan is secured by fixed and negative charge over all the assets of the Charity.

23. Events after the reporting period

There are no events after the reporting date which require disclosure in the financial statements.

24. Restated comparative figures

In the prior year there was an over accrual of debtors. This resulted in assets and income being materially overstated. This came to light due to circumstances which occurred after the financial statements were signed and issued. The comparative figures have been restated.

ACTION DUCHENNE LIMITED

England & Wales - Charity number 1101971

Accounts

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 MARCH 2021

ACTION DUCHENNE LIMITED

ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

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ADMINISTRATIVE AND STATUTORY DETAILS

Board of Trustees	Mark Silverman Gary Fegan Roger Cockerton (Treasurer) Dr Tina Flatau Robert Laid Simon Dadd Victoria Penrice Ellen Lambrix
National Director	Florence Boulton
Scientific Advisory Board	Dame Professor K Davies – Chair Professor M Wood – Vice Chair
Registered office	CAN Mezzanine 49-51 East Road Hoxton London N1 6AH
Independent Examiners	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

MESSAGE FROM THE NATIONAL DIRECTOR
FOR THE YEAR ENDED 31 MARCH 2021

The year 2020/21 has been a monumental year for Action Duchenne. We could define it as the year of **bringing support, care and education to life.** The winds of change have pervaded every aspect of Action Duchenne's operations, affecting not only our charity's activities, but our staff and entire community; the children, young people and adults living with Duchenne and their families and supporters. Not even the management has been immune to it. It is my absolute pleasure to give you a brief walk through our major milestones of the year and to provide you with a taste of the surprising achievements you will encounter throughout the report.



The dedicated Action Duchenne team

The heart of any great organisation lies with its people. We are truly appreciative of our team of dedicated and passionate staff at Action Duchenne who have put forth a tremendous effort in propelling the organisation forward with many new launches, transitions and projects this past 12 months.

Supporting families
In 2020/21, we have:

- supported over 2,000 young people, adults and their families through our direct and bespoke support calls, video chats and online meetings;
- delivered over 30 support webinars, which covered important topics from physiotherapy, learning and behaviour to making the most of online appointments;
- established 6 peer-to-peer support groups for grandparents, Mums, Dads and young people living with Duchenne have gone from strength to strength;
- wowed over 120 children and young people in our virtual magical grotto to meet Father Christmas;
- shared 37 volunteer contributors' personal lived experiences and blog posts.

International Conference 2020/21
Action Duchenne International Conference was the preeminent Duchenne event in the UK. The 19th global conference brought together the best researchers in Duchenne muscular dystrophy from across the world. The event attracted over 700 families, clinicians, therapists, researchers, pharmaceutical companies and, most importantly, those living with Duchenne from at least 50 nations. Families and supporters were able to meet and learn about all aspects of the condition from international experts, as well as to find out from other families and those living with Duchenne, how to get the best life possible. For academics and clinicians, this event provided the opportunity to network, along with discussing the latest findings in genetic research and sharing expertise in optimal standards of care.



Supporting research

We have continued on our proven track record of funding state-of-the art translational Duchenne research. Funding a range of projects this financial year, we have;

- supported the UNITE-DMD programme, alongside Muscular Dystrophy UK and AFM Telethon. This project aims to develop and test a gene therapy for Duchenne muscular dystrophy, in a clinical trial, An update in late 2020 reported that Genethon would begin a clinical trial at a French site, with UK Sites opening once ethical approval was secured. As part of our response to the pandemic, we renegotiated our funding of the UNITE-DMD programme to reduce our total commitment to £200K.
- completed a multi-year Clinical Trials Lectureship project at Newcastle University which we funded alongside other Duchenne charities (Alex's Wish, Duchenne UK, Duchenne Now, Duchenne Research Fund, Joining Jack and Harrison's Fund), demonstrated the potential of this approach - funding a multi-year Clinical Trials Lectureship that enabled the holder to develop the centre's clinical trials programme.
- despite some delays (due to labs being closed during lockdown, the project that we awarded to Dr Yung Yao Lin at Queen Mary University London is progressing well. Together with Barts Charity, we are funding an innovative project that aims to develop techniques to combine stem cell and gene-editing technologies in Duchenne. The researchers are currently writing up their results for publication in a scientific journal early next year.
- founded our Big Ideas Fund - an innovative scheme that aims to invest small amounts of money in early stage research projects. For parents of a child affected by Duchenne, knowing that a scientist may have an idea that can't be tested due to a lack of funding is devastating. An untested idea might represent a life changing treatment. Or even, the hope for all Duchenne parents, a cure…Our Big Ideas Fund will award small top-up grants to enable researchers to bring those novel, untested ideas to the lab. Donations we receive for the fund are restricted with every penny donated going towards funding exciting new research projects.
- continued our ongoing curation and support of the UK DMD registry as a key part of our research strategy. The registry has more than 2,000 people registered including more than 1,000 people living with Duchenne and is governed by a Steering Committee chaired by Dr Michela Guglieri (Institute of Human Genetics, Newcastle University). The UK DMD Registry is designed to respond to pharmaceutical feasibility studies to help drug developers identify whether it is possible to run a clinical trial in the UK. Over the next financial year, we plan to launch a new platform that will make longitudinal data collection possible.

Bringing our whole community together

In 2020/21, we had the pleasure of working with 18 regular volunteers giving their time and expertise on a range of tasks, from website, HR support, impact measurement, webinars, writing blogs to researching fundraising opportunities.



Our work also relies on voluntary donations from individuals, groups and companies. It is through your generosity that Action Duchenne continues to play a significant role in the support of our Duchenne community, helping children, young people and adults living with Duchenne to participate in our support and education projects that will lead them to become more independent, increased life satisfaction and quality of life.

Rebuild, refocus and reinvest - Action Duchenne Strategy 2021-2024

Action Duchenne puts our Duchenne families in the lead, so that they can define and refine our work and our role. Our 2021-2024 strategy plan provides a clear roadmap for our future strategy and marks the beginning of a new and exciting chapter.

In the next 3 years, we will focus on increasing support and delivering more innovative projects. We will achieve this by delivering projects that encourage the Duchenne community to use their passion, skills and experience to support, inspire, and empower each other. We will use our positive public image and messaging to engage business sponsors to fund our vital projects by:

- putting value at the heart of our Duchenne families and their supporters;
- re-establishing our science and research communication service;
- understanding what our supporters value most about our work;
- expanding our support and education services to explore new support opportunities;
- building our stakeholder engagement networks with our members, supporters and volunteers;
- developing an impact and evaluation framework for continual improvement;
- being transparent about our work so everyone can be confident that Action Duchenne is acting responsibly and investing our resources wisely.

Looking to the future



Our future success will be defined by projects that reach across the UK and internationally to improve care; provide families with the knowledge, education and support they need throughout their Duchenne journey; and provide people living with Duchenne with opportunities to attend university, find a job and reach their full potential in society.

All in all, 2020/21 could not have been a better time for me to take the reins at Action Duchenne. I extend my heartfelt gratitude to our volunteers, Patrons, Ambassadors and the Board of Trustees, for their passion and commitment, for supporting me at the International Conference, designing our new, much-needed 'All-through Support' project, enabling the charity to bring the life-changing opportunity of the support to so many children, young people, adults and families in the UK and globally, at the most important stages of their Duchenne.

We truly are stronger together. Action Duchenne is committed to supporting the future for everyone living with Duchenne… Another busy year ahead!

.....

Florence Boulton
National Director

The Trustees present their report and the financial statements for the twelve months ended 31 March 2021 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 2019).

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:

Mark Silverman
Gary Fegan
Dr Tina Flatau
Robert Laid
Simon Dadd
Roger Cockerton (Treasurer)
Victoria Penrice
Zachary Fargher (resigned 29 July 2021)
Ellen Lambrix (appointed 29 September 2021)

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 also like to thank all Patrons and Trustees, past and present, who have given their time and energy to Action Duchenne.

Introduction
The charity landscape changed dramatically in the three years up to 2020/21, mainly due to the proliferation of new UK Duchenne charities. This required Action Duchenne to review its own offering and purpose to ensure it retained a place in the changed community.

In 2020/21 we have refined the operational plan after consultation with supporters, families, Patrons, Ambassador and trustees, and input from all the team members. We have established a strategic roadmap for 2021-24, allowing us to know the direction we are meant to follow in relation to an individual component of our operations (for example, research, education, support, campaigning and operational management).

There are several key challenges that we have tried to address in 2020/21:

- securing sustainable funding in the medium to long term
- ever-changing landscape for communication, fundraising and support makes moving towards a more integrated, digital way of working imperative
- competing successfully in a competitive market

About us: our vision and objectives
Action Duchenne has a very clear vision: a world where lives are no longer limited by Duchenne muscular dystrophy.

We have three core objectives:

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

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. Duchenne is usually diagnosed around the age of 4, and people living with the condition experience progressive muscle weakness. They typically need to use a powered wheelchair from their early teens, and since the heart and breathing muscles are affected most will require a ventilator in their twenties.

When Action Duchenne was founded in 2001, the average life expectancy for a young person living in the UK with Duchenne was late teens. It is now late 20s with more people than ever living into their 30s and 40s.

There is no cure.

Why Action Duchenne?

- **Committed:** staff, trustees and patrons, along with a supportive network of volunteers and partner organisations
- **Rigorous:** governance procedures, policies and processes are well controlled in line with regulatory frameworks and best practices
- **Collaborative:** working closely with trustees, stakeholders and national and international partner organisations to achieve goals
- **Innovative:** projects and programmes are created to satisfy an unmet need
- **Influential:** within the Duchenne community, pharmaceutical, health and social care sectors
- **Proactive:** forging partnerships with funders, organisations, corporates and individuals to drive fundraising, revenue, and find new income streams
- **Reporting:** established systems to evaluate, report and feedback impact, communicating more effectively to all stakeholders

Our reflection

Action Duchenne is at the heart of the Duchenne community. 50% of our staff and Trustees have a child living with the condition and this provides real, on-the-spot expertise on what the families we support need and the situations they face. We have had some major successes. We brought together the group of scientists who developed the 'exon skipping' drugs that offer hope for some living with Duchenne; our disease registry has put the UK at the forefront of clinical trials; our research funding has given more than 130 people the chance to take part in a clinical trial and we are currently funding a gene therapy clinical trial so even more families can be offered this opportunity.

Our support team talks to over 2,000 families living with Duchenne every year. We might help families to apply for benefits, attend meetings at schools alongside families or simply listen as families talk about their child's condition. Our work provides a vital lifeline to families, and we aim to help every single person and family affected by the condition. Following diagnosis, parents often say "the only person who understands what I'm going through is another Duchenne parent".

The team works hard to bring families together, to support each other. We organise the largest Duchenne conference in Europe, bringing families from across the UK together with expert clinicians, researchers and drug developers. We work with others wherever possible and have acted as a springboard for other patient groups.

Financial Review

The accounting period reverted to 12 months following the previous period that was extended to 17 months to move our financial year so our annual international conference (in November) falls in a single financial year.

In 2020/21 the Charity had a net surplus for the year of £126,477 following a deficit of £23,538 in the previous year. The year has been characterised by a challenging environment across the charity sector; for Action Duchenne this materialised as a reduction in donations and legacies received. Scientific research and grants payable decreased by 53.5% from £643,779 to £299,403 which compounded the surplus for the year.

Income was £494,338 in 2020/21 (12 month period) and £758,434 in 2018/20 (17 month period). With amounts generated from donations and legacies decreasing 43.1%, income from other trading activities decreasing 63.5% and an increase in income from charitable activities of over 700%.

Expenditure on charitable activities was £326,138 in the 12 month period (2018/20, 17 months: £685,441), including allocated support costs. This represents 88.7% of total expenditure, compared to 87.7% in the previous year. Of this, £299,403 was spent on research and grants payable (2018/20: £643,779). As well as the research organisations listed above, this includes UPPMD membership and Genetic Alliance UK membership.

Operational costs continue to be managed tightly, and the National Director has initiated a focused programme of work to correct the fall in charitable income in particular.

Loan Borrowings

During the year, the Charity secured a £50,000 Bounce Bank loan under the Coronavirus government-backed lending scheme.

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 of £92,000, 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 £218,246 up from £91,600 in March 2020 and restricted reserves are £21,259 (2020: £21,428). 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. Our research strategy sets out five key areas, where we will focus our investment in research going forward:

- Innovation – we will co-fund novel research projects
- Outcome measures and natural history data
- Investing in tissue collection and biobanking
- Standards of Care – continuing our long-standing involvement in supporting the best possible multidisciplinary standards of care
- Maintaining the UK DMD Registry

The rapidly changing developments in international research demand a constant updating of the charity's grant making policy. Our peer reviews grant applications as part of a two-stage review process and systematically reviews and agrees its research and grant making policy during the development of its annual business plan.

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.

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:

- 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 from the National Director and then the Finance Committee and/or the board of Trustees
- The management team prepare a business plan with internally audited yearly accounts and projections of budget expenditure at the end of each year. This is fully discussed by the Finance Committee and then at a specially convened meeting of the Board of Trustees
- The Finance Committee is responsible for overseeing the annual independent examination of the accounts by Simpson Wreford LLP
- Regular consideration by the Finance Committee of financial results, variances from budgets, forecasts and performance indicators
- Chain of command overseen by the Treasurer, 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
    - HR
    - Safeguarding
    - Trustee and volunteer roles and responsibilities
    - Charity procedures (including financial control)
    - Equal opportunities
    - Social media and digital/electronic communications

The Board of Trustees meet face to face or via remote conferencing at least four times a year. While the Charity aims to involve parents and those living with Duchenne muscular dystrophy as members of the Board of Trustees, a balance is sought by recruiting non-family members who have other scientific, business and professional expertise. The Board is divided into four sub committees, each with specific terms of reference: corporate engagement, audit, finance & risk, delivery & research, and conference.

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 independent examination information of which the charitable company's independent examiner is unaware; and
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant independent examination information and to establish that the independent examiner 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.

Independent Examiner

Simpson Wreford LLP were reappointed as Independent Examiners 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.



.....

Roger Cockerton
Treasurer

Date: 8 December 2021

INDEPENDENT EXAMINERS' REPORT

TO THE TRUSTEES OF ACTION DUCHENNE LIMITED FOR THE YEAR ENDED 31 MARCH 2021

I report on the accounts of the company for the year ended 31 March 2021, which are set out on pages 12 to 25.

Responsibilities and basis of report
As the charity's Trustees (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 (the '2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's report
Since the company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

(1) accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or

(2) the accounts do not accord with those accounting records; or

(3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or

(4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

M Broder FCA

for and on behalf of Simpson Wreford LLP, Chartered Accountants
Wellesley House
Duke of Wellington Avenue
Royal Arsenal
London
SE18 6SS
Dated: 9 DECEMBER 2021

ACTION DUCHENNE LIMITED

STATEMENT OF FINANCIAL ACTIVITIES
(including statement of income and expenditure)
FOR THE YEAR ENDED 31 MARCH 2021

	Notes	2021 Unresticted funds	2021 Restricted funds	12 mths to 31 March 2021 Total funds	17 mths to 31 March 2020 Total funds
Income and endowments from:	4				
Donations and legacies		217,844	5,000	222,844	391,158
Charitable activities		-	125,560	125,560	14,285
Other trading activities		128,874	-	128,874	352,763
Investments		32	-	32	228
Other - Government grants		17,028	-	17,028	-
Total income		**363,778**	**130,560**	**494,338**	**758,434**
Expenditure on:	16				
Raising funds:					
Cost of events and general fundraising		41,723	-	41,723	96,531
Charitable activities:					
Campaigning and education		16,041	-	16,041	24,997
Scientific and clincial research and grants payable		158,255	141,148	299,403	643,779
Improved management and medical care		10,694	-	10,694	16,665
Total expenditure		**226,713**	**141,148**	**367,861**	**781,972**
Net income/(expenditure)		**137,065**	**(10,588)**	**126,477**	**(23,538)**
Transfers between funds		(10,419)	10,419	-	-
Net movement in funds		**126,646**	**(169)**	**126,477**	**(23,538)**
Reconciliation of funds					
Balance at 1 April 2020		91,600	21,428	113,028	136,566
Balance at 31 March 2021		**218,146**	**21,259**	**239,505**	**113,028**

The notes on pages 15 to 25 form part of these financial statements.

ACTION DUCHENNE LIMITED

STATEMENT OF FINANCIAL POSITION
AS AT 31 MATCH 2021

	Notes	2021		2020	
		£	£	£	£
Fixed assets					
Tangible assets	**5**		1,920		1,135
Investments	**6**		2		2
			1,922		1,137
Current assets					
Debtors	**7**	51,093		43,867	
Cash at bank and in hand		396,747		98,374	
		447,840		142,241	
Current liabilities					
Creditors due within one year	**8**	(166,090)		(30,350)	
Net current assets			281,750		111,891
Total assets less current liabilities			283,672		113,028
Creditors due more than one year	**9**		(44,167)		-
Net assets	**15**		239,505		113,028
Represented by:					
Restricted funds	**13**		21,359		21,428
Unrestricted funds	**14**		218,146		91,600
			239,505		113,028

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the period ended 31 March 2021. 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.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

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 13 - 25 were approved by the Trustees on 8 Dec 2021 and signed on their behalf by:

.....
Roger Cockerton– **Trustee/Treasurer**

Registered charity number – 1101971
Registered charity – SC043852 (Scotland)

ACTION DUCHENNE LIMITED

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 31 MARCH 2021

	Notes	12 mths to 31 March 2021 Total £ (12)	17 mths to 31 March 2020 Total £ (17)
Cashflows from operating activities:			
Net cash (used in)/provided by operating activities	**19**	299,765	(87,110)
Cashflows from investing activities:			
Dividends, interest and rents from investments		33	228
Purchase of equipment		(1,425)	-
Purchase of investments		-	-
Net cash provided by/(used in) investing activites		(1,392)	228
Change in cash and cash equivalents in the reporting period		298,373	(86,882)
Cash and cash equivalents as at 1 April 2020	**20**	98,374	185,256
Cash and cash equivalents as at 31 March 2021	**20**	**396,747**	**98,374**

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 2019) - (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 twelve months ended 31 March 2021 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 March 2021 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 independent examiners' fees.

h) Programme related investments are included in the accounts at cost less amounts written off as grants payable.

1. Accounting policies (continued)

i) Fixed assets are only capitalised were 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.

2. Employees

Costs to the company were as follows:

	2021 £ (12 mths)	2020 £ (17mths)
Gross wages:		
- projects	169,635	62,333
- non-projects	20,498	210,045
Staff pension	4,123	5,687
Employer's NI contributions	14,315	23,061
	208,571	301,126

The average number of full-time employees during the year was 6 (2020 - 7) analysed as follows:

	2021 Number (12 mths)	2020 Number (17mths)
Management - FTE	0.6	-
Research - FTE	0.6	1
Support - FTE	2.3	-
Fundraising - FTE	1.8	4
Advocacy/Campaigns - FTE	0.7	2
	6	7

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

3. Net incoming resources is stated after charging

	2021 £ (12 mths)	2020 £ (17mths)
Independent examination and accountancy fees	7,620	8,697
Depreciation	640	378

4. Analysis of income and endowments

	Unresticted funds £	Restricted funds £	2021 Total £ (12 mths)	2020 Total £ (17mths)
Donations and legacies				
- Grants of a general nature	13,551	5,000	18,551	-
- Membership subscriptions	41,711	-	41,711	36,614
- Fundraising income	104,688	-	104,688	341,830
- Gift Aid	7,894	-	7,894	3,736
- Other	50,000	-	50,000	8,978
Charitable activities				
- Performance related grants	-	125,560	125,560	14,285
- Other	-	-	-	-
Other trading activities				
- Funraising events	4,375	-	4,375	-
- Non-charitable trading activities	123,066	-	123,066	352,763
- Shop income	1,433	-	1,433	-
Investments	32	-	32	228
Other – Government grants	17,028	-	17,028	-
	363,778	130,560	494,338	758,434

5. Tangible assets

	Computer Equipment £	Fixtures & fittings £	Office equipment £	Total £
Cost				
At 1 April 2020	25,147	1,098	6,839	33,084
Additions	-	-	1,425	1,425
31 March 2021	25,147	1,098	8,264	34,509
Depreciation				
At 1 April 2020	24,161	1,083	6,705	31,949
Charge for the year	246	4	390	640
At 31 March 2021	24,407	1,087	7,095	32,589
Net book value				
At 31 March 2021	740	11	1,169	1,920
At 31 March 2020	986	15	134	1,135

6. Investments

	2021 £	2020 £
Programme related investments		
Convertible loan note in Halo Therapeutics LLC	225,000	225,000
Less: treated as grant paid 2012	(224,999)	(224,999)
	1	1

Halo Therapeutics is a clinical-stage biopharmaceutical firm focused on developing innovative therapies for rare fibrotic diseases such a 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.

	2021 £	2020 £
Other investments		
1,371 Ordinary shares of £0.001	1	1

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

	2021 £	2020 £
Trade debtors	42,858	7,500
Other debtors	4,441	9,976
Prepayments	3,794	26,391
	51,093	43,867

8. Creditors: amounts falling due within one year

	2021 £	2020 £
Trade creditors	21,426	7,311
Accruals and deferred income	137,426	20,655
Tax and social security	-	47
Bank loan	5,833	-
Other creditors	1,405	2,337
	166,090	30,350

Deferred income included above relates to Science on Tour income £105,000 (2020 - £Nil) and Demelza project sponsorship income to January 2022 of £15,000 (2020 - £Nil).

9. Creditors : amounts falling due after more than one year

	2021 £	2020 £
Bank loans and overdrafts	44,167	-

10. Trustees' expenses and indemnity insurance

A Trustee may receive reimbursement of reasonable out-of-pocket expenses actually incurred in running the charity. In 2021, the total out-of-pocket expenses reimbursed was £Nil (2020 - £7,541) 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.

11. 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.

12. Other professional services provided by the independent examiners

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

13. Restricted funds

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

The movements for the year are as follows:

	Newcastle CRF £	Lottery Fund £	Science on Tour £	Demelza £	Total £
At 1 April 2020	21,428	-	-	-	21,428
Donations / legacies / grants	50,000	75,560	-	5,000	130,560
Grants payable and research costs	(50,169)	(75,560)	(9,999)	(5,420)	(141,148)
Transfers from unrestricted funds	-	-	9,999	420	10,419
As at 31 March 2021	21,259	-	-	-	21,259

Details of funds

Newcastle CRF – a consortia of seven UK Duchenne charities funds a senior lectureship at Newcastle University. Other members of the consortia have been invoiced for their share but due to Covid-19 and the ensuing economic climate they have not been paid. This obligation for other consortia members has been recognised in these financial statements and will be paid over promptly when received.

Lottery fund – funding received from the Coronavirus Community Support Fund, distributed by The National Lottery Community Fund, in recognition of our continuing work to support Duchenne families during lockdown and beyond. The project was successful delivered by 31 March 2021.

Science on Tour – supported by a consortia of pharmaceutical companies and the Garfield Weston Foundation. The project encompasses an extensive programme of 24 events over 12 months, visiting more than 20 towns and cities across the UK. Development of activities and materials which were carried out in phases in FY2020/21 using a just in time methodology to allow maximum flexibility to respond to COVID-19. The project is expected to be completed in 2021/22.

Demelza – this project has developed joint working between Demelza House Children's Hospice and Action Duchenne to support young people and their families. We plan to carry out reviews to collect information and data to help us decide how to improve the support for young people living with Duchenne and their families who are going through the transition process. The project is expected to be completed in 2021/22.

14. Unrestricted funds

	General fund £
At 1 April 2020	91,600
Income	363,778
Expenditure	(226,713)
Transfer	(10,419)
At 31 March 2021	218,246

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.

15. Analysis of net assets between funds

	Fixed assets £	Current assets £	Current liabilities £	Long-term liabilities £	Total £
Restricted funds	-	21,259	-	-	21,259
Unrestricted funds	1,922	426,581	(166,090)	(44,167)	218,246
	1,922	447,840	(166,090)	(44,167)	239,505

16. Fund Transfers

Transfer from unrestricted reserves to Science On Tour and Demelza relates to contributions to projects which setup costs have been incurred but have not been completed as at the year end.

17. Analysis of resources expended

	2021 £ (12 mths)	2020 £ (17mths)
Support costs:		
Bank charges and interest	1,216	1,317
Insurance	1,612	(710)
Wages and salaries	208,571	301,126
Printing, postage and stationery	7,380	6,184
Training, recruitment and other staff costs	3,371	16,497
Rent and rates	6,026	38,238
Computer costs	10,403	28,303
Storage	2,201	1,252
Telephone and internet costs	2,292	4,280
Depreciation	640	378
Trustees' meetings	-	7,541
Governance costs	15,650	11,467
Professional fees	6,188	-
Miscellaneous expenditure	1,800	740
	267,350	416,613

Grants totalling £76,232 were payable to 3 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%	213,880	85,523	299,403
Fundraising 10%	26,735	14,988	41,723
Campaigning and education 6%	16,041	-	16,041
Improved management and medical care 4%	10,694	-	10,694
	267,350	100,511	367,861

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

18. 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:

	2021 £ (12 mths)	2020 £ (17mths)
Grant – The University of Newcastle	50,000	50,000
Grant – CSO	-	9,063
Grant – UPPMD membership	-	1,810
Grant – University Hospitals Bristol NHS Foundation	-	12,260
Grant – Queen Mary University London	25,320	-
Grant – University College London	-	11,285
Grant – World Duchenne Organisation	912	-
Grant – MD UK	-	25,000
	76,232	109,418

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

	2021 £ (12 mths)	2020 £ (17mths)
Grant to The Univerisity of Newcastle	-	50,000
Grant to Queen Mary University London	-	25,320
	-	75,320

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

	2021 Total £ (12 mths)	2020 Total £ (17mths)
Net surplus/(deficit) for the reporting period	36,476	(23,538)
Adjustments for:		
Depreciation charges	640	378
Dividends, interest and rents from investments	(33)	(228)
(Increase) / decrease in debtors	(7,226)	40,606
Increase / (decrease) in creditors	169,908	(104,328)
Net cash provided by (used in) operating activites	299,765	(87,110)

20. Analysis of cash and cash equivalents

	2021 £ (12 mths)	2020 £ (17mths)
Cash in hand	396,747	98,374
Total cash and cash equivalents	396,747	98,374

21. Commitments under operating leases

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

	2021 £ (12 mths)	2020 £ (17mths)
Operating leases which expire: within two to five years	-	5,909

22. Loans and overdrafts

	2021 £ (12 mths)	2020 £ (17mths)
Bank loans	50,000	-
Payable within one year	5,833	-
Payable after one year	44,167	-

The long-term bank loan is secured by fixed and negative charge over all of the assets of the Charity.

23. Events after the reporting period

The amounts due to the University of Newcastle and Queen Mary University were repaid in full during the 2021/22 financial year.