

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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ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

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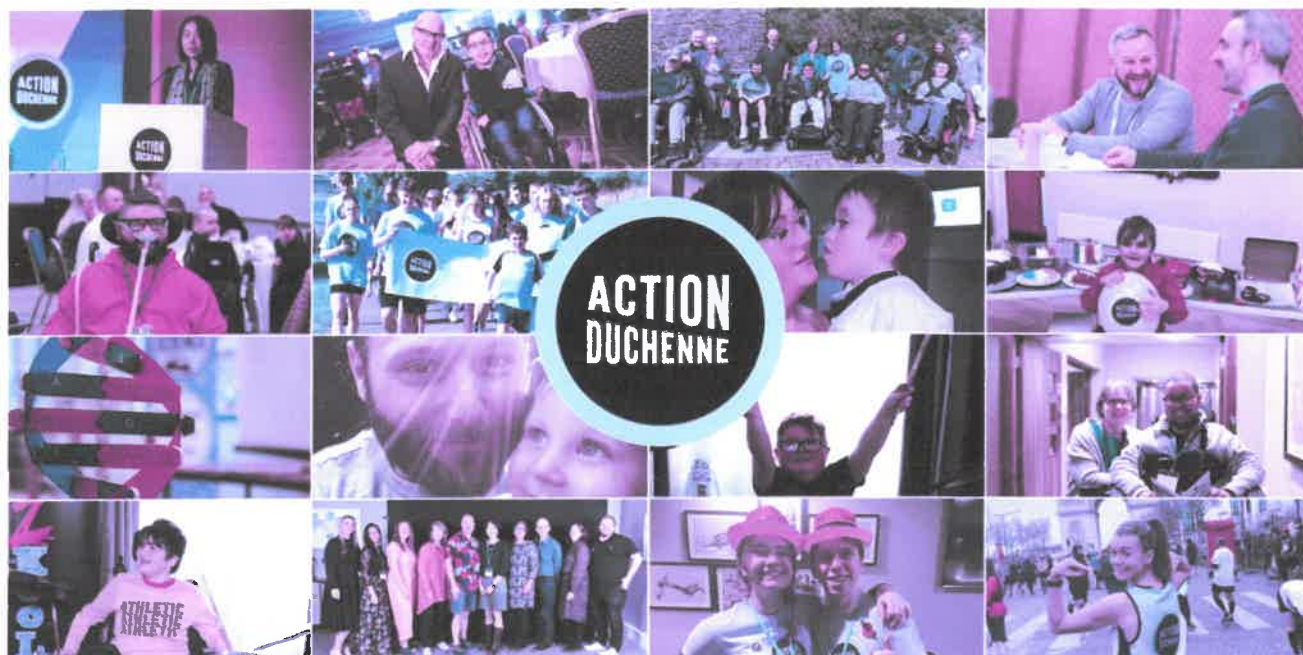
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ACTION DUCHENNE LIMITED
ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

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

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."



ACTION DUCHENNE LIMITED

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

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.

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

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.

Handwritten signature of Florence Boulton

.....
Florence Boulton
Chief Executive Officer
Date:

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2024

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.

ACTION DUCHENNE LIMITED

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2024

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.

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2024

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.

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2024

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.

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2024

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.

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2024

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

INDEPENDENT AUDITORS' REPORT

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

INDEPENDENT AUDITORS' REPORT
TO THE TRUSTEES OF ACTION DUCHENNE LIMITED
FOR THE YEAR ENDED 31 MARCH 2024

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.

INDEPENDENT AUDITORS' REPORT

TO THE TRUSTEES OF ACTION DUCHENNE LIMITED FOR THE YEAR ENDED 31 MARCH 2024

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.

INDEPENDENT AUDITORS' REPORT
TO THE TRUSTEES OF ACTION DUCHENNE LIMITED
FOR THE YEAR ENDED 31 MARCH 2024

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 Unrestricted 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		<u>433,232</u>	<u>179,147</u>	<u>612,379</u>	<u>711,864</u>
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,		68,783	165,281	234,064	380,653
and grants payable		54,378	-	54,378	36,259
Improved management and		-	-	-	-
medical care		-	-	-	-
Total expenditure		<u>391,991</u>	<u>250,367</u>	<u>642,358</u>	<u>580,845</u>
Net income/(expenditure)		41,241	(71,220)	(29,979)	131,019
Transfers between funds		-	-	-	-
Net movement in funds		<u>41,241</u>	<u>(71,220)</u>	<u>(29,979)</u>	<u>131,019</u>
Reconciliation of funds:					
Balance at 1 April 2023		<u>480,195</u>	<u>71,220</u>	<u>551,415</u>	<u>420,396</u>
Balance at 31 March 2024		<u>521,436</u>	<u>-</u>	<u>521,436</u>	<u>551,415</u>

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

ACTION DUCHENNE LIMITED
STATEMENT OF FINANCIAL POSITION
AS AT 31 MARCH 2024

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

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 18/10/24 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 activities		9,779	28
Cashflows from financing activities:			
Loan received		-	-
Interest paid		-	(719)
Net cash (used in)/provided by financing activities		-	(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

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

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.

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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 where 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.

ACTION DUCHENNE LIMITED

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

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	<u>24,424</u>	<u>19,901</u>
	<u>340,640</u>	<u>294,999</u>

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	<u>0.8</u>	<u>0.3</u>
	<u>9.75</u>	<u>9.0</u>

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	<u>540</u>	<u>720</u>

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

4. Analysis of income and endowments

	Unrestricted 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	-	-	-	-
	<u>433,232</u>	<u>179,147</u>	<u>612,379</u>	<u>711,864</u>

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	<u>2,772</u>	<u>-</u>	<u>1,425</u>	<u>4,197</u>
Depreciation				
At 1 April 2023	1,213	-	823	2,036
Charge for the year	390	-	151	541
Disposals	-	-	-	-
At 31 March 2024	<u>1,603</u>	<u>-</u>	<u>974</u>	<u>2,577</u>
Net book value				
At 31 March 2024	<u>1,169</u>	<u>-</u>	<u>451</u>	<u>1,620</u>
At 31 March 2023	<u>1,559</u>	<u>-</u>	<u>602</u>	<u>2,161</u>

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

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)
	<u>1</u>	<u>1</u>

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

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	<u>1</u>	<u>1</u>

PepGen Limited (company number 11170794) is a company focused on biotech research and development, to improve the delivery and effectiveness of exon skipping drugs as a way of restoring dystrophin. In April 2018, Action Duchenne was donated a number of shares in the company in recognition of previous support and funding to the University of Oxford, which amounted to a grant of £48,000 in April 2017.

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.

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

7. Debtors

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

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	<u>4,329</u>	<u>3,515</u>
	<u>77,532</u>	<u>82,735</u>

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.

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

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	<u>19,080</u>	<u>31,268</u>	<u>(50,348)</u>	<u>-</u>	<u>-</u>
	<u>71,220</u>	<u>179,147</u>	<u>(250,367)</u>	<u>-</u>	<u>-</u>

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.

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

13. Unrestricted funds

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

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

14. Analysis of net assets between funds

	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	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
	<u>521,436</u>	<u>-</u>	<u>521,436</u>	<u>551,415</u>

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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	<u>6,296</u>	<u>7,102</u>
	<u>463,492</u>	<u>414,845</u>

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	<u>54,378</u>	<u>-</u>	<u>54,378</u>
	<u>463,492</u>	<u>178,866</u>	<u>642,358</u>

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

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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 University of Glasgow	21,180	-
	<u>21,180</u>	<u>-</u>

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	<u>-</u>	<u>10,590</u>
	<u>-</u>	<u>10,590</u>

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

	2024	2023
	Total	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	<u>(5,203)</u>	<u>57,535</u>
Net cash provided by (used in) operating activities	<u>(99,840)</u>	<u>194,066</u>

18. Analysis of cash and cash equivalents

	2024	2023
	£	£
Cash in hand	<u>534,978</u>	<u>625,039</u>
	<u>534,978</u>	<u>625,039</u>

19. Events after the reporting period

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