

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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ACTION DUCHENNE LIMITED

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

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

MESSAGE FROM THE NATIONAL DIRECTOR
FOR THE YEAR ENDED 31 MARCH 2022

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*.

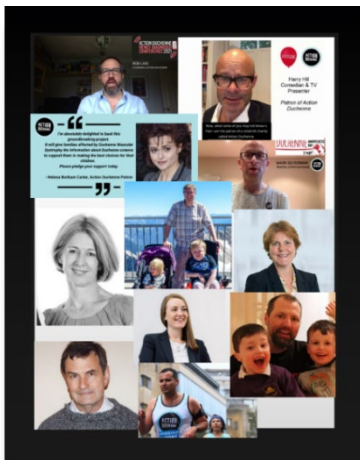
Rebuild, refocus and reinvest

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:



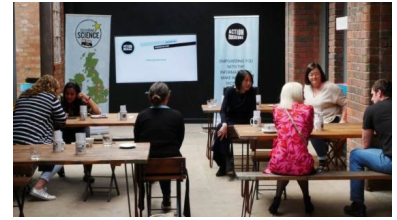
- made contact with the North Star network to gain an understanding of Duchenne and the diagnostic pathway.
- 11 peer-to-peer support groups have been established. Support materials have been produced, and shared with the hospitals identified.

ACTION DUCHENNE LIMITED

MESSAGE FROM THE NATIONAL DIRECTOR FOR THE YEAR ENDED 31 MARCH 2022

- 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'

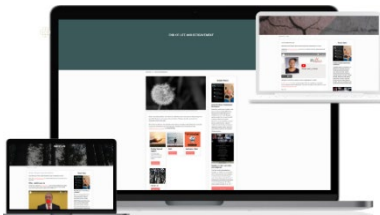


- supported 650 young people, adults and their families through our direct and bespoke support calls, video chats and messaging, and online and in person meetings.

- 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.

SATURDAY 13TH NOVEMBER			SUNDAY 14TH NOVEMBER		
TIME	SUBJECT	SUMMARY	TIME	SUBJECT	SUMMARY
09.00 - 09.05	Meeting Duchenne and Standards of Care	The Duchenne Standards of Care is a document that sets out the care that people living with the condition should receive. You will hear from leading clinicians from around the world about a range of topics from bone health, heart drugs and use of steroids.	09.00 - 09.05	The effects of COVID-19 on Duchenne Research and Care	The pandemic has seen huge changes in how medical care is delivered, and how drugs are developed, tested and approved. Our expert panel will be discussing the challenges and successes of the move to hybrid trials with appointments at home, virtual clinic appointments, faster regulation and increased drug manufacturing capabilities.
09.05 - 09.10	Break / social time	We know how much you gain from interaction with families, clinicians and researchers, so please head to The Meeting Place during the break and social time. There will be lots of opportunities to go online in our conference game, update your details on the UK DMD registry, meet the speakers, visit the exhibitors, speak with conference partners and share support and knowledge with each other.	09.05 - 09.10	Break / social time	Remember to head over to The Meeting Place to meet the exhibitors, speak to the experts and chat with Duchenne families.
09.10 - 09.15	Latest clinical trial news	Professors Francesca Muntoni (UK) and Volker Straub (Netherlands) have been the lead investigators in many of the Duchenne clinical trials within the United Kingdom and globally. They will host a session exploring the latest advances and results from clinical trials around the world, where you will have the opportunity to pose your questions to the expert panel.	09.10 - 09.15	Myotonia and the brain, learning and behaviour	Starting with the science, you will find out why myotonia is in the brain, what it is to purpose and what happens when it is missing. Expert learning and behavioural issues in Duchenne with our panel which includes a leading SENCO and behavioural experts. Find out about how to navigate school and how to manage and support individuals and families living with the condition.
09.15 - 09.20	Break / social time	Remember to head over to The Meeting Place to meet the exhibitors, speak to the experts and chat with Duchenne families.	09.15 - 09.20	Break / social time	This is your last chance to click-up points in the conference game! Visit the exhibitors, update your details on the DMD Registry and share your experience with others. Group games are up for grabs, so make the most of the final hour's break!
09.20 - 09.25	Caring for older children and adults living with Duchenne	It is important that adults receive the care and services they need to stay as healthy, independent, and active as they want to be. Hear from leading experts covering topics such as: respiratory management, the benefits and challenges of tracheostomy, gastrointestinal issues and management, nutrition and diet, glucose and exercise, the benefits and challenges of PEG tubes.	09.20 - 09.25	Living with Duchenne	Hear from young people and adults living with Duchenne as they share their personal experiences and knowledge. Gain practical information from our partner organisations on topics to help you navigate your journey such as housing, adaptations and benefits. Get inspired and find out what is possible to help you meet your aspirations.
09.25 - 09.30	Evening social: Living as an adult with Duchenne	After a quick break, continue the conversations raised earlier in the Adults standards of care session. The evening social is a private session for adults living with Duchenne and their families/caring to chat and meet other like-minded people. Expect frank and open conversations around topics such as relationships and dating, getting, finding a job and living independently.	09.25 - 09.30	Music and us	Join the stars of our 'Music and Me' podcast for an evening of music and chat.
09.30 - 09.35	Music and us	Join the stars of our 'Music and Me' podcast for an evening of music and chat.			

MESSAGE FROM THE NATIONAL DIRECTOR FOR THE YEAR ENDED 31 MARCH 2022

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

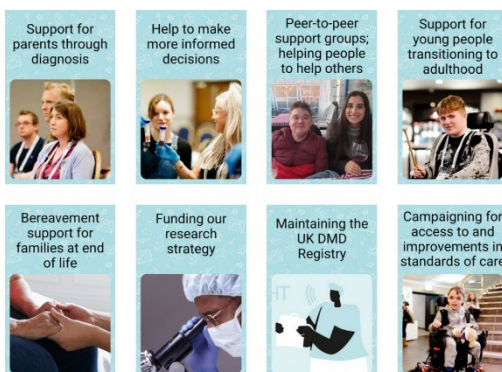


-continued our ongoing curation and support of the UK DMD registry as a key part of our research strategy. The registry has more than 2,000 people registered including more than 1,000 people living with Duchenne and is governed by a Steering Committee chaired by Dr Michela Guglieri (Institute of Human 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.

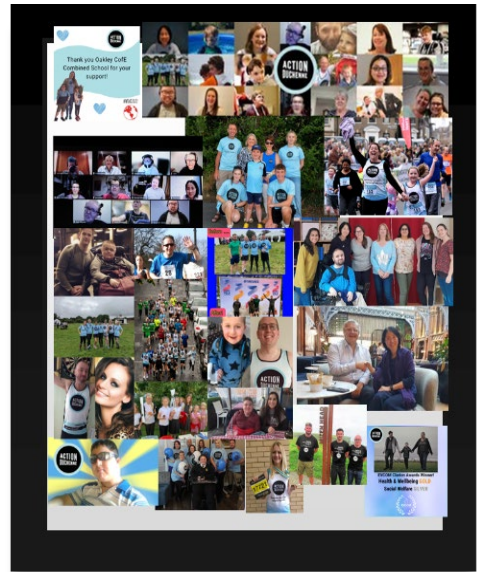
Building a strong team united by shared values

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.

MESSAGE FROM THE NATIONAL DIRECTOR
FOR THE YEAR ENDED 31 MARCH 2022

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

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2022

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.

ACTION DUCHENNE LIMITED

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2022

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.

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2022

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.

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2022

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.

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2022

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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).

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2022

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.

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Roger Cockerton
Treasurer

Date: 8 December 2022

INDEPENDENT AUDITORS' REPORT

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

INDEPENDENT AUDITORS' REPORT

TO THE TRUSTEES OF ACTION DUCHENNE LIMITED FOR THE YEAR ENDED 31 MARCH 2022

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 2022

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 2022

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 Unrestricted 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		<u>1,250</u>	<u>-</u>	<u>1,250</u>	<u>17,028</u>
Total income		<u>326,792</u>	<u>235,394</u>	<u>562,186</u>	<u>472,906</u>
 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		<u>31,616</u>	<u>-</u>	<u>31,616</u>	<u>10,694</u>
Total expenditure		<u>125,078</u>	<u>234,785</u>	<u>359,863</u>	<u>367,861</u>
Net income/(expenditure)		201,714	609	202,323	105,045
Transfers between funds		<u>369</u>	<u>(369)</u>	<u>-</u>	<u>-</u>
Net movement in funds		<u>202,083</u>	<u>240</u>	<u>202,323</u>	<u>105,045</u>
 Reconciliation of funds:					
Balance at 1 April 2021		218,073	-	218,073	113,028
Balance at 31 March 2022		<u>420,156</u>	<u>240</u>	<u>420,396</u>	<u>218,073</u>

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

ACTION DUCHENNE LIMITED

**STATEMENT OF FINANCIAL POSITION
AS AT 31 MARCH 2022**

	Notes	2022		2021 Restated	
		£	£	£	£
Fixed assets					
Tangible assets	5		2,881		1,920
Investments	6		<u>2</u>		<u>2</u>
			2,883		1,922
Current assets					
Debtors	7		11,049		29,661
Cash at bank and in hand			<u>475,928</u>		<u>396,747</u>
			486,977		426,408
Current liabilities					
Creditors due within one year	8		<u>(35,222)</u>		<u>(166,090)</u>
Net current assets			<u>451,755</u>		<u>260,318</u>
Total assets less current liabilities			454,638		262,240
Creditors due more than one year	9		<u>(34,242)</u>		<u>(44,167)</u>
Net assets	15		<u>420,396</u>		<u>218,073</u>
Represented by:					
Restricted funds	13		240		-
Unrestricted funds	14		<u>420,156</u>		<u>218,073</u>
			<u>420,396</u>		<u>218,073</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 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	<u>88,454</u>	<u>249,765</u>
Cashflows from investing activities:			
Dividends, interest, and rents from investments		19	33
Purchase of equipment		(2,772)	(1,425)
Proceeds from disposal of tangibles		<u>-</u>	<u>-</u>
Net cash (used in) by investing activities		<u>(2,753)</u>	<u>(1,392)</u>
Cashflows from financing activities:			
Loan received		-	50,000
Loan repayment		<u>(6,520)</u>	<u>-</u>
Net cash (used in)/provided by financing activities		<u>(6,520)</u>	<u>50,000</u>
Change in cash and cash equivalents in the reporting period		79,181	298,373
Cash and cash equivalents as at 1 April 2021	20	<u>396,747</u>	<u>98,374</u>
Cash and cash equivalents as at 31 March 2022	20	<u>475,928</u>	<u>396,747</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

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.

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

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 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.

ACTION DUCHENNE LIMITED

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

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	<u>14,826</u>	<u>14,315</u>
	<u>227,559</u>	<u>208,571</u>

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	<u>0.8</u>	<u>0.7</u>
	<u>8.0</u>	<u>6.0</u>

3. Net incoming resources is stated after charging

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

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022**

4. Analysis of income and endowments

	Unrestricted 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	<u>1,250</u>	<u>-</u>	<u>1,250</u>	<u>17,028</u>
	<u>326,792</u>	<u>235,394</u>	<u>562,186</u>	<u>472,906</u>

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	<u>(25,147)</u>	<u>(1,098)</u>	<u>(6,839)</u>	<u>(33,084)</u>
31 March 2022	<u>2,772</u>	<u>-</u>	<u>1,425</u>	<u>4,197</u>
Depreciation				
At 1 April 2021	24,407	1,087	7,095	32,589
Charge for the year	693	-	267	960
Disposals	<u>(24,407)</u>	<u>(1,087)</u>	<u>(6,739)</u>	<u>(32,233)</u>
At 31 March 2022	<u>693</u>	<u>-</u>	<u>623</u>	<u>1,316</u>
Net book value				
At 31 March 2022	<u>2,079</u>	<u>-</u>	<u>802</u>	<u>2,881</u>
At 31 March 2021	<u>740</u>	<u>11</u>	<u>1,169</u>	<u>1,920</u>

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

6. Investments

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

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

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	<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 2022

7. Debtors

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

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	<u>2,930</u>	<u>1,405</u>
	<u>35,222</u>	<u>166,090</u>

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	<u>34,242</u>	<u>44,167</u>

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.

ACTION DUCHENNE LIMITED

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

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)	-
	-	<u>235,394</u>	<u>(234,785)</u>	<u>(369)</u>	<u>240</u>

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.

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

14. Unrestricted funds

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

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	<u>(34,242)</u>	<u>-</u>	<u>(34,242)</u>	<u>(44,167)</u>
	<u>420,156</u>	<u>240</u>	<u>420,396</u>	<u>218,073</u>

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.

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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	<u>4,065</u>	<u>1,800</u>
	<u>316,159</u>	<u>267,350</u>

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%	<u>31,616</u>	<u>-</u>	<u>31,616</u>
	<u>316,159</u>	<u>43,704</u>	<u>359,863</u>

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

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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
	<u>46,746</u>	<u>50,912</u>

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

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

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

	2022	2021
	Total	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	<u>(135,057)</u>	<u>129,907</u>
Net cash provided by (used in) operating activities	<u>88,454</u>	<u>249,765</u>

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20. Analysis of cash and cash equivalents

	2022 £	2021 £
Cash in hand	<u>475,928</u>	<u>396,747</u>
	<u>475,928</u>	<u>396,747</u>

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	<u>-</u>	<u>-</u>

22. Loans and overdrafts

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

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.