

Company number: 04899036

Registered charity number: 1101971

Registered charity number (Scotland): SC043852

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

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ADMINISTRATIVE AND STATUTORY DETAILS

| | |
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| Board of Trustees | Mark Silverman Gary Fegan Roger Cockerton (Treasurer) Victoria Penrice |
| National Director | Florence Boulton |
| Scientific Advisory Board | Dame Professor K Davies – Chair Professor M Wood – Vice Chair |
| Registered office | Wellesley House Duke of Wellington Avenue Royal Arsenal London SE18 6SS |
| Auditors | Simpson Wreford LLP Wellesley House Duke of Wellington Avenue Royal Arsenal London SE18 6SS |
| Company number | 04899036 |
| Charity number | 1101971 SC043852 (Scotland) |
| Solicitors | Morgan Cole Bradley Court Park Place Cardiff CF10 3DR |
| Banks | Barclays Bank PO Box 3 77 North Street, Keighley BD21 3SA The Co-operative Bank Plc PO Box 250 Skelmersdale N3 6WT |

ACTION DUCHENNE LIMITED

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

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

Rebuild, refocus and reinvest

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

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

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

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

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

1. Support Duchenne families all-through their journey

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

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



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

ACTION DUCHENNE LIMITED

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

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

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

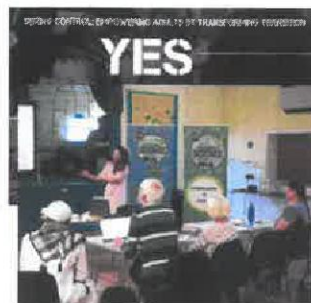
In 2023 we provided a vital support mechanism for our newly diagnosed families including:



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

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

- 20 Duchenne Science workshop delivered across the UK and Ireland.
 - 118 attendees at the event with 68 new contacts with Action Duchenne made.
 - 100 percent of the responses from the survey found the workshops useful.
- 360 of Duchenne Science: mutations, genetics, diagnosis, screening, emerging drugs, steroids, standards of care.



Testimonials from newly diagnosed families

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

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

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

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



ACTION DUCHENNE LIMITED

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

Testimonials from supporting families - core

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

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

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

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

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

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

Testimonials from young people and adults

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

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



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

1.6 Action Duchenne Annual International Conference 2022

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

Testimonials from conference attendees



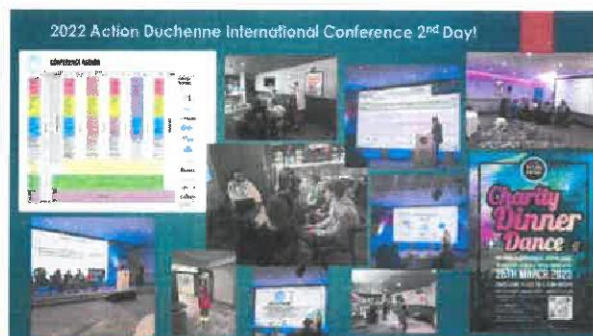
"It was such a well organized event. My husband and I can't thank Action Duchenne enough for organising this event. We would definitely be in a very different space mentally and emotionally had it not been for the excellent support you guys provide us. The opportunity to talk to the top minds in Duchenne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

"Both my wife and I have immensely enjoyed the Action Duchenne International Conference 2022 and

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



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



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

Benjamin, Speaker and adult living with Duchenne

ACTION DUCHENNE LIMITED

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

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

2.1 Translarna

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

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

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

2.2 Bone Health

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

2.3 UK DMD Registry



The UK DMD Registry

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

whether it is possible to run a clinical trial in the UK.

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

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

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

3.1 Living our strategic focus, creating shared value

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

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



3.2 Building a strong team united by shared values

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

The team here at Action Duchenne are currently working towards re-establishing our team of regular volunteers who use their time and expertise on a range of tasks, from website, HR support, impact measurement, webinars, writing blogs to researching fundraising opportunities. Currently



we are excited to have begun to develop a community of contributors from within the groups we facilitate who are keen to share their invaluable lived experience. Going forward, using a robust framework designed to provide life-changing support for our community throughout their journey, we will continue to nurture and grow the culture at Action Duchenne to support our new strategy that puts the community first in everything we do.



ACTION DUCHENNE LIMITED

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

3.3 Bringing our whole community together

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

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

THANK YOU!



Florence Boulton
National Director

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2023

The Trustees present their report and the financial statements for the twelve months ended 31 March 2023 which have been prepared in accordance with accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Reference and administrative details

Action Duchenne Limited is registered under the Companies Act as a company limited by guarantee (company number 04899036). The Charity registration number is 1101971 (England and Wales) and SC043852 (Scotland). The registered office address which is also the principal office address is Wellesley House, Duke of Wellington Avenue, Royal Arsenal, London SE18 6SS.

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

The following persons were Directors and Trustees during the year:

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

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

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

Introduction

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

ACTION DUCHENNE LIMITED
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FOR THE YEAR ENDED 31 MARCH 2023

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

- Building the capacity to deliver support to more individual and families – our success in securing funding from HM Government (in partnership with The National Lottery Community Fund) in 2022/23 has meant that we have been able to begin to deliver our much-needed 'All-through Support'.
- Focusing on delivering vital education and research project to a wider audience, increasing our support base as well as our platform within the charity landscape. Securing funding from trusts/foundations and corporate partners has meant that we have been able to begin to deliver our 'Supporting families through diagnosis and impossible decisions' project.
- Adapting and evolving our community fundraising activities and events – responding to the way supporters and donors like to support us, especially in our community context. We have started introducing more flexibility and options in the way support can be given, both in terms of methods of giving as well as engagement with more inclusive events.
- Steadily taking steps towards our ultimate goal of everybody living with Duchenne having the support they need and the respect they deserve. We believe, with the right encouragement, tools and positivity, children, young people, and adults living with Duchenne will create a bright future for themselves and be confident and happy enough to live that future to their full potential.

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

About us: our vision and objectives

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

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

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

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

What is Duchenne?

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

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

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

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FOR THE YEAR ENDED 31 MARCH 2023

Why Action Duchenne?

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

Financial review

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

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

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

Loan borrowings

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

Reserves

The Finance Committee, on behalf of the Board of Trustees, monitors the level of unrestricted reserves in the general fund, which is compared to the minimum level of required reserves calculated in accordance with the reserves policy. This is based on three months of charity expenditure of £145,200, which is aimed at providing cover in the event of a sudden reduction in income:

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

Unrestricted reserves at the year-end are £480,195, up from £420,156 in March 2022; and restricted reserves are £71,220 (2022: £240). The unrestricted reserves exceed the minimum required under the policy.

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Grant making policy

The Charity has a programme of grant making to provide funds for new research towards finding viable treatments and ultimately curing Duchenne muscular dystrophy. Our research strategy sets out five areas, where we will focus our investment in research going forward:

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

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

Investment policy

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

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

Internal control and processes

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

- Financial reports are reviewed at the quarterly Board meetings as part of measures to ensure that the resources of the Charity are effectively allocated and utilised
- Expenditure approval limits beyond which approval must be sought from the National Director and then the Finance Committee and/or the board of Trustees
- The management team prepare a business plan with internally audited yearly accounts and projections of budget expenditure at the end of each year. This is fully discussed by the Finance Committee and then at a specially convened meeting of the Board of Trustees
- The Finance Committee is responsible for overseeing the annual audit of the accounts by Simpson Wreford LLP
- Regular consideration by the Finance Committee and the board of financial results, variances from budgets, forecasts, and performance indicators
- Chain of command overseen by the Treasurer, delegation of authority and segregation of duties
- Ensuring that the Charity submits Annual Reports to the Charity Commission and Companies House in line with current standard reporting procedures
- Trustees are encouraged to undertake Trustee and governance training by accredited providers of education to the charity sector
- Charity procedures (including financial control)
- Equality, diversity and inclusion
- Social media and digital/electronic communications

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

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

Trustees' responsibilities

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

Company law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

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

In so far as the Trustees are aware:

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

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

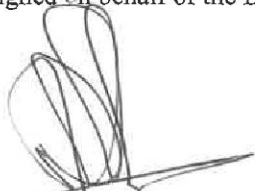
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Auditor

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

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

Signed on behalf of the Board of Directors.


.....

Roger Cockerton
Treasurer

Date: 1 December 2023

INDEPENDENT AUDITORS' REPORT
TO THE TRUSTEES OF ACTION DUCHENNE LIMITED
FOR THE YEAR ENDED 31 MARCH 2023

Opinion

We have audited the financial statements of Action Duchenne Limited (the 'Charitable company') for the year ended 31 March 2023 which comprise the Statement of Financial Activities, Statement of Financial Position, Cash Flow Statement, and the related notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 31 March 2023 and of its incoming resources and application of resources for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice;
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

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

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

Other information

The Trustees are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

INDEPENDENT AUDITORS' REPORT
TO THE TRUSTEES OF ACTION DUCHENNE LIMITED
FOR THE YEAR ENDED 31 MARCH 2023

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 2023

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 2023

Use of our report

This report is made solely to the Charitable company's members, as a body, in accordance with Chapter 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Michael Broder, Senior Statutory Auditor

For and on behalf of Simpson Wreford LLP, Statutory Auditor

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

Dated: 01/12/2023

Simpson Wreford LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

ACTION DUCHENNE LIMITED
STATEMENT OF FINANCIAL ACTIVITIES
(including statement of income and expenditure)
FOR THE YEAR ENDED 31 MARCH 2023

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

| | Notes | 2023 | | 2022 | |
|--|-------|-----------------|-----------------------|-----------------|-----------------------|
| | | £ | £ | £ | £ |
| Fixed assets | | | | | |
| Tangible assets | 5 | | 2,161 | | 2,881 |
| Investments | 6 | | <u>2</u> | | <u>2</u> |
| | | | 2,163 | | 2,883 |
| Current assets | | | | | |
| Debtors | 7 | 6,948 | | 11,049 | |
| Cash at bank and in hand | 20 | <u>625,039</u> | | <u>475,928</u> | |
| | | 631,987 | | 486,977 | |
| Current liabilities | | | | | |
| Creditors due within one year | 8 | <u>(82,735)</u> | | <u>(35,222)</u> | |
| Net current assets | | | <u>549,252</u> | | <u>451,755</u> |
| Total assets less current liabilities | | | 551,415 | | 454,638 |
| Creditors due more than one year | 9 | | <u>-</u> | | <u>(34,242)</u> |
| Net assets | 15 | | <u>551,415</u> | | <u>420,396</u> |
| Represented by: | | | | | |
| Restricted funds | 13 | | 71,220 | | 240 |
| Unrestricted funds | 14 | | <u>480,195</u> | | <u>420,156</u> |
| | | | <u>551,415</u> | | <u>420,396</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 2023. No member of the company has deposited a notice, pursuant to section 476, requiring an audit of these accounts under the requirements of the Companies Act 2006.

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

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

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

.....
 Roger Cockerton— **Trustee/Treasurer**

Registered charity number – 1101971

Registered charity – SC043852 (Scotland)

ACTION DUCHENNE LIMITED
STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 31 MARCH 2023

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

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023

1. Accounting policies

- a) Company information – Action Duchenne Limited is a private company limited by guarantee, incorporated in England and Wales (Company Registration Number: 04899036) and registered as a charity with the Charities Commission (Registered Charity Number: 1101971) and in Scotland (Registered Charity Number – Scotland: SC043852). The principal and registered office is Wellesley House, Duke of Wellington Avenue, Royal Arsenal, London SE18 6SS.
- b) The financial statements have been prepared in accordance with accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

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

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

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

The effects of events relating to the twelve months ended 31 March 2023 which occurred before the date of approval of the financial statements by the Trustees has been included in the financial statements to the extent required to show a true and fair view of the state of affairs as at 31 March 2023 and the results for the year ended on that date.

- c) Going Concern – at the time of approving the financial statements, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.
- d) Donations and legacies are accounted for when receivable by the Charity. Revenue grants are credited to the Statement of Financial Activities (SOFA) when the Charity is considered to have entitlement to the assets. It is probable that the resources will be received, and the monetary value of incoming resources can be measured with sufficient reliability. If grants are related to a future donor-imposed period, the income is deferred until that period. Other income is accounted for on an accrual basis.
- e) Direct charitable expenditure includes the direct costs of the activities. Support costs are allocated per note 17 on the basis of time spent.
- f) Fundraising costs are the direct costs of obtaining funds, and attributable allocated support costs.
- g) Governance costs include those costs incurred in the governance of the Charity, such as auditors' fees.

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

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 2023**

1. Accounting policies (continued)

- s) Fund accounting – General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Restricted funds made to the charity are to be used in accordance with specific restrictions imposed by donors. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

2. Employees

Costs to the company were as follows:

| | 2023 | 2022 |
|-----------------------------|-----------------------|-----------------------|
| | £ | £ |
| Gross wages: | | |
| - projects | 242,636 | 187,551 |
| - non-projects | 26,615 | 18,169 |
| Staff pension | 5,847 | 7,013 |
| Employer's NI contributions | <u>19,901</u> | <u>14,826</u> |
| | <u>294,999</u> | <u>227,559</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 (2022: £8,261) were made to employees.

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

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

3. Net incoming resources is stated after charging

| | 2023 | 2022 |
|--|-------------|-------------|
| | £ | £ |
| Auditors' fees | 7,800 | 6,500 |
| Independent examination and accountancy fees | 12,646 | 8,253 |
| Depreciation | <u>720</u> | <u>960</u> |

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023

4. Analysis of income and endowments

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

5. Tangible assets

| | Computer equipment £ | Fixtures & fittings £ | Office equipment £ | Total £ |
|-----------------------|----------------------------|-----------------------------|--------------------------|--------------|
| Cost | | | | |
| At 1 April 2022 | 2,772 | - | 1,425 | 4,197 |
| Additions | - | - | - | - |
| Disposals | - | - | - | - |
| 31 March 2023 | <u>2,772</u> | <u>-</u> | <u>1,425</u> | <u>4,197</u> |
| Depreciation | | | | |
| At 1 April 2022 | 693 | - | 623 | 1,316 |
| Charge for the year | 520 | - | 200 | 720 |
| Disposals | - | - | - | - |
| At 31 March 2023 | <u>1,213</u> | <u>-</u> | <u>823</u> | <u>2,036</u> |
| Net book value | | | | |
| At 31 March 2023 | <u>1,559</u> | <u>-</u> | <u>602</u> | <u>2,161</u> |
| At 31 March 2022 | <u>2,079</u> | <u>-</u> | <u>802</u> | <u>2,881</u> |

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

6. Investments

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

| | 2023 £ | 2022 £ |
|---------------------------------|-----------|-----------|
| 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 2023

7. Debtors

| | 2023 | 2022 |
|---------------|--------------|---------------|
| | £ | £ |
| Trade debtors | 4,385 | 3,500 |
| Other debtors | 506 | 3,364 |
| Prepayments | <u>2,057</u> | <u>4,185</u> |
| | <u>6,948</u> | <u>11,049</u> |

8. Creditors: amounts falling due within one year

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

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

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

| | 2023 | 2022 |
|---------------------------|-------------|---------------|
| | £ | £ |
| Bank loans and overdrafts | <u>-</u> | <u>34,242</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 2023, the total out-of-pocket expenses reimbursed was £392 (2022: £3) for travel and accommodation.

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

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

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023

11. Control relationships

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

12. Other professional services provided by the auditor

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

13. Restricted funds

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

The movements for the year are as follows:

| | At 1 April 2022 £ | Incoming Resources £ | Outgoing Resources £ | Transfers £ | At 31 March 2023 £ |
|--------------------------|-------------------------|----------------------------|----------------------------|----------------|--------------------------|
| Restricted funds: | | | | | |
| National Lottery Fund | - | 257,058 | (227,596) | - | 29,462 |
| Supporting Families | 240 | 47,300 | (40,000) | - | 7,540 |
| Contact a Family | - | 31,023 | (15,885) | - | 15,138 |
| Transition to Adulthood | - | 50,875 | (31,795) | - | 19,080 |
| | <u>240</u> | <u>386,256</u> | <u>(315,276)</u> | <u>-</u> | <u>71,220</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 second year of this project was completed in March 2023. Funding has been secured to support the delivery of the third year of activities in 2023/24.

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

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14. Unrestricted funds

| | General Fund £ |
|------------------|-------------------------------|
| At 1 April 2022 | 420,156 |
| Income | 325,608 |
| Expenditure | (265,569) |
| Transfer | - |
| At 31 March 2023 | <u>480,195</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 £ | 2023 Total £ | 2022 Total £ |
|-------------------------|-------------------------------------|-----------------------------------|-----------------------------|-----------------------------|
| Fixed assets | 2,163 | - | 2,163 | 2,883 |
| Current assets | 543,802 | 88,185 | 631,987 | 486,977 |
| Current liabilities | (65,770) | (16,965) | (82,735) | (35,222) |
| Non-current liabilities | - | - | - | (34,242) |
| | <u>480,195</u> | <u>71,220</u> | <u>551,415</u> | <u>420,396</u> |

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16. Analysis of resources expended

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

Support and governance costs are allocated as follows:

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

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

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17. Grants paid and future commitments

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

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

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

| | 2023 | 2022 |
|------------------------------------|---------------|-------------|
| | £ | £ |
| Grant to The University of Glasgow | <u>10,590</u> | <u>-</u> |
| | <u>10,590</u> | <u>-</u> |

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

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

19. Analysis of cash and cash equivalents

| | 2023 | 2022 |
|--------------|----------------|----------------|
| | £ | £ |
| Cash in hand | <u>625,039</u> | <u>475,928</u> |
| | <u>625,039</u> | <u>475,928</u> |

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20. Loans and overdrafts

| | 2023 | 2022 |
|-------------------------|-------------|---------------|
| | £ | £ |
| Bank loans | <u>-</u> | <u>44,264</u> |
| Payable within one year | - | 10,022 |
| Payable after one year | <u>-</u> | <u>34,242</u> |

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

21. Events after the reporting period

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