ALEX'S WISH

England & Wales · Charity number 1148845

Details

Status	Registered
Legal form	Charitable company
Company number	08116159
Registered	2012-09-05
Register	View on the Charity Commission register

Contact

Address	21 New Walk Leicester LE1 6TE
Phone	07903349475
Email	emma@alexswish.co.uk
Website	www.alexswish.co.uk

Activities

Objects: THE RELIEF OF SICKNESS AND THE PRESERVATION AND PROTECTION OF GOOD HEALTH BY SUPPORTING SCIENTIFIC RESEARCH INTO THE IMPROVED DIAGNOSIS, PREVENTION OR TREATMENT OF DUCHENNE MUSCULAR DYSTROPHY

Activities: To preserve and protect the health of children and adults with Duchenne Muscular Dystrophy by providing funding for support and scientific research into treatments and cures .To advance the education of the general public in all areas relating to Duchenne by disseminating information on the disease and its treatments and cures.

Classification

- **How:** Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People

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Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-06-30	£368,599	£362,438	-	-
2024-06-30	£287,081	£268,141	-	-
2023-06-30	£344,578	£433,762	-	-
2022-06-30	£225,880	£223,967	-	-
2021-06-30	£154,148	£122,645	-	-

Trustees

Name	Role	Appointed
ANDREW ROGER HALLAM		2012-07-19
Alexandra Slack		2020-04-21
Arthur William Grey Hazlerigg		2024-02-09
Christopher Ralph Everard		2018-04-01
EMMA JAYNE HALLAM		2012-07-19
Richard Adam Copson		2025-03-14
Sandesh Jesrani		2020-04-27
Sean Gareth Masters		2025-05-08
Stephanie Jayne Merrill		2026-02-26

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ALEX'S WISH

England & Wales - Charity number 1148845

Accounts

Company registration number: 08116159
Charity registration number: 1148845

ALEX'S WISH
TRUSTEES' REPORT AND UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2025

Sturgess Hutchinson

Alex's Wish
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The trustees present their report and the financial statements for the year ended 30 June 2025.

Objectives and Activities

Aims and Objectives

1. The principal objects of the charitable company are the relief of sickness and the preservation of good health by supporting scientific research into the improved diagnosis, prevention, or treatment of Duchenne Muscular Dystrophy by:

a) Extending the current scope of drugs / treatments so that they will help all children with Duchenne Muscular Dystrophy.
b) Fund first stage clinical trials that provide the safety and efficacy of some of these treatments and then progress this into larger scale production.
c) Fund the completion of scientific work already begun, to bring it to clinical trials, and fund other forms of treatment that will work on all children regardless of their genetic mutation.
d) Fund studies that will bring about data and information to help decision makers make decisions on which treatments to bring to market.
e) Fund the DMD Care programme empowering patients/families to access the best care wherever they live in the UK.
f) Fund new technological advances to help children and young adults living with Duchenne live a better quality of life.

2. Advance the education of the public in all areas relating to Duchenne Muscular Dystrophy by disseminating information on the disease and its treatments and cures. To:

a) Disseminate information using online and offline materials, including the Alex's Wish Website and via our monthly e-newsletters to our supporters.
b) Running events and fundraising activities, including our Spring Launch and Autumn Lunch which sees our team, trustees, representatives from Duchenne UK, and our supporters come together for us to share our impact during the last 12 months and our plans.
c) Promoting our work across a variety of social media platforms, including Facebook, You Tube, Linkedin, Instagram and Tik Tok.
d) We have built great relationships with the local media outlets in our region including ITV Central and BBC East Midlands and regularly generate news articles and updates in local newspapers, including The Leicester Mercury, The Loughborough Echo and local magazines posted through doors. We appear regularly on the local radio stations including BBC Radio Leicester to raise awareness about Duchenne and the impact this has on families living with it.
e) Talking and presenting at various events on Corporate Social Responsibility, the impact of living with Duchenne Muscular Dystrophy and About Alex's Wish - it is important our personal story is shared amongst others to be the voice for other families affected by Duchenne.
f) Owning It 'The Power of Resilience' talks and workshops delivered to businesses in exchange for a donation to the charity.

Significant Activities

Statement from the CEO and Charity Founder, Emma Hallam

Dear Supporters,

Since we launched Alex's Wish in late 2012, after our son Alex was diagnosed with Duchenne Muscular Dystrophy, we continue to make great progress. Our relentless energy and passion inspire us every single day, to deliver results for the Duchenne community.

We **exist to defeat Duchenne** for this generation of children and young adults. Our approach is simple, fund the best science, support practical clinical trials and make sure children and young adults living with Duchenne in the UK, can access treatments, new technologies and care, wherever they live.

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Significant Activities - continued

We fund across the treatment journey – from research to real-world care. This includes projects ranging from gene therapy and gene editing, stem cell therapy, heart research and early detection, steroid optimisation and alternatives, clinical care and improving access to clinical trials in the UK, improving quality of life through new technologies – namely The ELEVEX Suit and The DREAM Wheelchair, as well as supporting female carriers through better understanding the impact this has for them.

Since launch, we have delivered:
- Raised over £2.8M
- Funded 42 projects
- Supported 24 medical research projects
- Supported 4 clinical trials
- Supported 5 projects improving care in the UK
- Supported 7 clinical posts supporting the Duchenne community
- Supported 2 technology projects to improve how children and young adults navigate the world whilst living with Duchenne

How we decide what to fund. Every project is reviewed by an independent Scientific Advisory Board, made up of leading global experts in Duchenne. This ensures that funding only goes to the best science worldwide. No duplication of existing research. Every project has a clear path of delivery. Treatments move faster from the lab to the patient. We work closely with Duchenne UK, to maximise impact and accelerate progress.

How we got here. Alex's Wish was founded by Emma and Andy Hallam after their son Alex was diagnosed with Duchenne shortly before his fourth birthday.

At the time, support was limited. We were told to take Alex home and live the best life possible. Long-term steroids were the only treatment option offered, despite significant side effects. There was no cure, and little hope of medical breakthroughs.

Since Alex's diagnosis in 2010, Emma and a small, dedicated team – supported by an incredible community of trustees, ambassadors, supporters, and partners – have worked tirelessly to create real, measurable change.

Alex has played his part too, spending much of his young life taking part in clinical trials that have helped advance treatments and deliver genuine progress.

We're deeply grateful to everyone who helps make progress possible.

An exciting time in medical breakthroughs
The science is at a very exciting time; a time of optimism as new treatments have emerged, one of which is proving to be delaying disease progression. We are aware that time is not on our side, and that for families affected by Duchenne – whether they have a child diagnosed several years ago, or families receiving a recent diagnosis – they need solutions to support their child. This is what drives us every single day, to fundraise and raise awareness to continue supporting new innovative projects to address the problems within the Duchenne community. This financial year, we have been able to support a further four projects.

Vamorolone (a steroid alternative drug)
2023 was a breakthrough year – the first ever drug approved for use on children with Duchenne – called Vamorolone, thanks to charities like Alex's Wish who helped fund the early stages of this project. When Alex was diagnosed back in 2010, we were told the standard medication for children with Duchenne, steroids, would keep them independently mobile for longer, but with harmful side effects. Vamorolone a new steroid drug, that has less harmful side-effects to traditional steroids, has been approved by the Medicines and Healthcare products Regulatory Agency (MHRA) in the UK. We are incredibly proud that we were able to invest in the early stages to make this a reality – proof that Alex's Wish is a charity that is making a positive impact for this generation of children and young adults living with Duchenne.

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Significant Activities - continued

Givinostat (proving to delay disease progression)
2024 was another breakthrough year – Givinostat, a drug to help delay disease progress has been conditionally approved in the UK by MHRA, but it is not yet readily available through the NHS. It is an 'HDAC inhibitor', it blocks enzymes called histone deacetylases, which are involved in turning genes 'on' and 'off' within cells to help reduce inflammation and muscle loss. Work is underway to hopefully get this drug approved by NICE so that every child and young adult living with Duchenne can access this drug through the NHS. In the meantime, this drug has been offered free of charge in the UK through the early access programme. However, it has been the decision of each hospital trust to decide whether they will provide it to their Duchenne community. Some have, and some still haven't, Duchenne UK and the Duchenne community has been working incredibly hard campaigning for access across the UK. We have been supporting NICE as a patient representative, offering insights into why gaining access to this drug is so important. Whilst Alex's Wish did not directly financially contribute towards this project, as a family we have been taking part in the clinical trial over several years.

Gene Therapy
We were told that Gene Therapy wouldn't happen in our son's lifetime. During the time that Alex's Wish has been in operation, we supported Solid Biosciences, a start-up to pursue this new technology, and boys are now being dosed with gene therapy in clinical trials taking place now in the UK. We know there are challenges with Gene Therapy, which is why we are continuing to support projects that are looking to address these problems – and bring better therapies to our children.

Best practice in Duchenne care
We are working alongside DMD Care UK, to help support better quality of care for everyone living with Duchenne in the UK. To date, we have funded several projects, including financial support for a DMD Hub Project Manager designed to increase clinical trial capacity in the UK and, a nutrition programme supporting those affected by Duchenne, and a project looking to address the lack of accessible housing amongst our community. This financial year, we have supported a transitioning project, supporting young adults living with Duchenne during the transitioning stage when they move from paediatric care into adult services – something which we have recently encountered ourselves with Alex.

We are incredibly positive about the future and Alex's Wish gives us hope. Duchenne Muscular Dystrophy is part of our lives, not out of choice, but we will make it as best as we can, and we will never stop our journey to conquering Duchenne.

I continue to support this important cause, by working **voluntarily** for the charity and as a very proud trustee and CEO – it is my pleasure to do this, to support all families affected by Duchenne.

Our work is only possible, thanks to our army of supporters, the charitable foundations who support us, the local business community, our business sponsors, our small team, our patron, ambassadors and our dedicated trustees and we would like to thank every single one of them.

Thanks for everything you do.

Emma Hallam
Charity Founder and CEO

Public Benefit

The Charity has established its grant making policy to achieve its objectives for the public benefit to find a cure for Duchenne Muscular Dystrophy and to slow down the rate of progression by maintaining muscle strength for longer, leading to increased life expectancy as well as a better quality of life.

We only want to fund great science - projects that can improve the knowledge base and bring treatments that can reach the clinic and improve the lives of boys with Duchenne Muscular Dystrophy in many ways. We want to fund new technologies that will go on to help those affected by Duchenne, by making the world accessible to them.

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Public Benefit - continued

We formed a partnership with Duchenne UK. Duchenne UK share the same mission and objectives as Alex's Wish and are also a parent-led charity. As a Charity Partner to Duchenne UK, we receive projects that require co-funding. All such projects have been reviewed extensively by their Scientific Advisory Board (SAB) which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy. They bring with them a wide range of essential skills and knowledge basis including scientific, clinical and drug discovery and development. When scientists approach Duchenne UK with their ideas for new research projects it is the SAB who apply their experience and expertise to test these ideas, helping to refine them, if necessary, in order that Duchenne UK can make informed decisions on funding. Alex's Wish Trustees review all projects put forward before deciding upon specific projects to fund.

We regularly send updates on project performance and outcomes to our supporters through a monthly e-newsletter as well as publish updates on our social media channels, news articles on our website and submit press releases to the local media companies. We have appeared on BBC East Midlands Today and ITV Central.

The trustees confirm that they have complied with the requirements of Section 17 of the Charities Act 2011 to have due regard to the Charity Commission's guidance on public benefit.

Achievements and Performance

Main Achievements

About Duchenne

Duchenne in numbers

- 1 of the most serious genetic diseases in children
- 1 in 3,500 boys born with Duchenne worldwide
- 2,500 boys affected in the UK (approx.)
- 300,000 boys affected globally (approx.)
- 2 families every week receive a diagnosis in the UK
- 12 is the average age boys require a wheelchair in 90% of cases

About Duchenne

Duchenne Muscular Dystrophy is a severe, progressive genetic condition that primarily affects boys. Duchenne crosses all races, cultures, and backgrounds. Girls can also be affected and make up around 1% of diagnoses.

What causes Duchenne?

Duchenne is caused by a genetic mutation that stops the body from producing dystrophin, a protein essential for healthy muscle function.

Without dystrophin:

Muscles weaken and break down over time
Muscles cannot repair themselves properly
Strength, movement, and independence are progressively lost
Around one in three cases occurs in families with no previous history of Duchenne.

Early signs and diagnosis:

The average age of diagnosis is around four years old.

- Delays in sitting and walking
- Difficulty keeping up with peers
- Speech delay or frequent falls

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Main Achievements - continued

How Duchenne progresses:

Duchenne affects everyone differently – even siblings with the same genetic mutation can experience very different progression.

- Muscle weakness usually begins in early childhood, affecting the hips, thighs, shoulders, and pelvis
- During the teenage years, weakness spreads to the arms, lower legs and trunk
- Because dystrophin is also missing from the heart and lung muscles, breathing and heart function are affected
- Some individuals may experience learning and/or behavioural challenges
- Ventilation support and 24-hour care is needed as the disease progresses

With improved care, many people with Duchenne are now living into their 20s and 30s, and ongoing research and clinical trials continue to improve quality of life and outcomes.

Our Vision

Our Vision is a world without Duchenne Muscular Dystrophy.

We want a future that stops the devastating impact Duchenne has on our children and young adults, a future where they can grow and prosper and fulfil their dreams.

A life where they can enjoy every day without the fear of the progression this muscle wasting disease has on their bodies. A future without Duchenne would be a bright and happy future for all those affected. We need to act quickly to save this generation. Doing nothing is not an option. Our boys and their families need to live without fear and have hope for the future.

Our Mission

Alex's Wish exists to end Duchenne for this generation.

We do this by halting and reversing muscle wasting through funding groundbreaking clinical trials, supporting world-class care, and accelerating access to life-enhancing technologies across the UK.

Our mission is inspired by Alex – a calm, quietly determined and courageous young man living with Duchenne. For more than a decade, Alex has taken part in clinical trials, helping bring vital treatments closer to the families who need them.

His resilience drives our **Be More Alex mindset:** a can-do philosophy captured in one simple idea – when the world gives you lemons, make lemon meringue pie.

Our Philosophy

Be More Alex runs through everything we do to raise funds and awareness – from our fun, community-powered signature events, to our "push-yourself" personal challenges.

It's more than a strapline; it's a mindset that turns adversity into action.

Be More Alex brings the joy: gratitude for what we have, optimism for what's possible, and the strength of a like-minded community determined to squeeze every last drop out of life.

Our Values

We lead with a positive, can-do mindset.

If Alex can stay positive while living with Duchenne, so can we.

Our focus is on what's possible and acting on what we can control.

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Main Achievements - continued

Collaboration
We're stronger together. By working with families, supporters, and partners like Duchenne UK, we achieve more and create greater impact.

Inspire and Educate
We tell it like it is. We're open, honest, and real about life with Duchenne - using our positive voice to inspire action, raise awareness, and empower others to join the mission.

Family-focused
People come first. We value time, flexibility and balance, and we deeply appreciate the commitment of our family of trustees, ambassadors, volunteers and supporters.

Ambitious
We're in it to change history. We act with urgency, think big, and push for real change – determined to defeat Duchenne for this generation.

Our Impact this year

The Trustees are delighted to have been able to make significant payments during this accounting period to four projects equating to £232,989 in line with its objectives. We provide project updates as and when they become available on our website alexswish.org, e-newsletters to our supporters and at our supporter events – namely our Spring Lunch and Autumn Launch.

- **Given an additional £40,000 towards the 'Help the Heart' Cardiac Grant Call.**

Last year we gave £63,000, and this financial year, we have given another £40,000 towards this important project. Our heart muscles need dystrophin to function efficiently. In Duchenne, a lack of dystrophin means that heart muscles weaken over time. Heart cells are replaced by scar and fatty tissue, which leads to a type of heart muscle disease called dilated cardiomyopathy. The age when this happens in Duchenne can vary from person to person, from early childhood to adulthood. Children with Duchenne don't usually have cardiac symptoms. However, weakening heart muscles are part of the natural progression of the disease. Therefore, early monitoring, preventative treatment, and ongoing management are important for keeping the heart healthy into adulthood. It is currently not possible to prevent heart weakness in Duchenne completely. However, steroids and heart medication can slow down the decline in heart function.

This grant call will help us understand how the heart is affected and identify potential innovative treatment strategies and approaches. In response to a huge unmet need in cardiac management and effective therapeutic options targeted to at the heart, leading to poor outcomes in people living with Duchenne. This is an area of focus for us and thrilled to share that two cardiac projects are now pushing forward, as follows: One in **repurposing Empagliflozin for Duchenne** and the other an **international survey on clinical presentation and service provision to inform ongoing care.**

Thanks to The Nottingham Hot Property Show for donating £36,000 towards these projects.

Project 1 - Repurposing Empagliflozin for Duchenne
Institution: Great Ormond Street Hospital
Principal Investigator: Sebastiano Lava
Status: Ongoing until March 2028

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Main Achievements - continued

Among the recent improvements in adult heart failure management, the sodium glucose type 2 inhibitor (SGLT2) empagliflozin was found to reduce cardiovascular death or heart failure by 25%. However, little is known on its use in children or adolescents with Duchenne. Current heart failure therapy in children is unsatisfactory and heart failure trials in children have historically often failed because the right dose was not used or inappropriate formulations of the drug and clinical endpoints were adopted in the trials. We have funded this project, enabling the team to explore whether this drug can be repurposed for the Duchenne heart in a clinical study which addresses all the limitations above. If the optimal dose is confirmed and early efficacy signals are detected in this pilot study, this will allow for a larger study to demonstrate the benefit of this therapy of Duchenne-associated cardiomyopathy.

Project 2 – An international survey on clinical presentation and service provisions to inform care
Institution: The University of Newcastle
Principal Investigator: Michela Guglieri
Status: Ongoing

Historically, research into female carriers of dystrophinopathies, who are women that have a genetic mutation of the dystrophin gene on one of their x chromosomes, has been low priority and we want to change this.

Duchenne female carriers can be subject to symptoms of Duchenne such as muscle weakness and diseases of the heart, and more clinical research is needed to better understand how these individuals can be better supported and treated. We are supporting a team as they lead the development of a survey which aims to gain deeper insights into the clinical signs and symptoms that are observed by medical professionals which show what being a carrier looks like, how carriers health is tested and observed, (specifically heart and muscle health), how genetic risks are managed and addressed, and the impact of caring for an affected person on physical symptoms and mental health. The results of the survey will inform a much-needed natural history study, develop a more targeted survey to circulate to individuals tested for carrier status, in collaborations with large genetic centres and match with cardiac guidance as part of the DMD Care UK.

• Given £168,000 towards an Innovative Medical Grant Call

Institution: Myogene
Principal Investigator: Courtney Young, Co-Founder and CEO of MyoGene Bio
Status: Ongoing

We are proud to have supported a project with MyoGene Bio, a San Diego-based biotech company dedicated to developing transformative therapies for muscle disease, to accelerate development of an innovative gene editing therapy for Duchenne Muscular Dystrophy. The project entitled 'Optimization of a gene editing therapy' will focus on refining MyoGene's cutting-edge CRISPA/Cas 9-based therapy. MyoDys45-55 aims to permanently delete a mutation hotspot in the DMD gene, restoring the reading frame and enabling production of a shorter but functional dystrophin protein, like that found in individuals with Becker Muscular Dystrophy (a milder form of Muscular Dystrophy). The therapy offers several advantages over existing genetic medicines, including permanent DNA editing, preservation of natural gene regulation, and restoration of a dystrophin protein three times the size of micro-dystrophin.

If successful, the therapy could be suitable for approximately 50% of boys with Duchenne. The funding will enable MyoGene to optimise muscle targeting, assess durability and explore potential treatment regimens that could improve editing efficiency. The company has already engaged the FDA in the US to accelerate their ability to conduct a clinical trial in DMD boys, and all being well, they should be in the clinic in 2027.

Thanks to The Brothers Trust, who kindly gave a grant for £35,000 towards this project.

• Given £22,000 towards a transitioning of care project – better supporting standards of care for those transitioning from paediatric care to adult care

Institute: Leeds Teaching Hospital
Principal Investigator: Anne-Marie Childs
Status: Ongoing until September 2027

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Main Achievements - continued

For young people living with Duchenne, the transition from paediatric to adult care is fraught with challenges. This transition period is a critical time, not just for medical management, but also for the psychosocial support these young individuals need to thrive as they move into adulthood. Sadly, this transition period often lacks the necessary structure and support, families are left navigating a fragmented healthcare system with varying levels of support across the country.

The consequences of not having a clear and well-supported transition pathway are severe. Without proper transition planning, young people often face abrupt changes in their care, leading to confusion, anxiety and in some cases deterioration in their health. Additionally, the variation in services across the country means that while some receive excellent care, others are left without the necessary resources and support, particularly when their condition becomes more complex.

To address these issues, we are working in collaboration with Duchenne UK and Joining Jack (another parent-led charity in the UK) towards developing a comprehensive transition pathway tailored specifically for young people with Duchenne. This project will create resources and support systems that ensure a smoother, more effective transition into adult care, providing both medical and psychosocial support.

By working together collaboratively with healthcare professionals, patients, and their families, this initiative will produce practical tools, guides, and models that can be implemented across different healthcare settings.

• **Given £5,989 towards a Post BIND (The Brain Involvement in Dystrophinopathies) Co-ordinator**

Institute: University College London
Principal Investigator: Francesc Muntoni, Paediatric Neurologist
Status: Ongoing until June 2026

This funding supports the Co-ordinator post for the Brain Involvement in Dystrophinopathies (BIND) consortium which brings together 19 partners from Europe and Japan who received funding for a 4-year project from the European Commission to address the preclinical and clinical aspects related to the role of dystrophin in the brain.

There is a wealth of data on gene mutation and clinical and imaging phenotypes that has not been fully analysed and published and this post was put in place in July 2024 to complete this work and to drive BIND's strategic aims, adding greatly to our knowledge and treatment options for the involvement of the brain in Duchenne. Several workshops and presentations were published in the summer of 2025 and the consortium remains committed to improving diagnosis and treatments of brain comorbidities in dystrophinopathies.

• **We have continued to raise awareness about Duchenne Muscular Dystrophy.**

Through regular posting across our social media platforms, about stories, progress, medical news, ways in which our supporters made an impact and how they can support us in the future and are seeing an ever increasing following and engagement online.

Thank you to everyone who follows our journey. Through our calendar of events, we have been raising the profile of our cause and engaging with existing and new supporters.

• **We have secured a pipeline of fundraising support and activities over the next 12 months.**

In addition to the funds received during this financial year, we have seen great success with our fundraising activities in the latter part of 2025 and into 2026.

We have secured funding from various trusts and foundations, including **The Brothers Trust, The Hospital Saturday Fund** and **The D'Oyly Carte Charitable Trust**.

Delivered a calendar of successful and profitable fundraising activities and events for our supporters to get involved with, so that we can continue to raise money to further our mission.

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Main Achievements - continued

Plus, much more about which you can find the details by following us across our social media platforms and on our website.

Recent activities and achievements

Over the years, we have funded a variety of projects across a broad-spectrum from early-stage research through to clinical trials, funded five clinical posts to support clinical trial development and patient access, funded DMD Care projects, as well as supported new technologies.

Here are some examples of the work we have funded over recent years.

• **The ELEVEX Suit - £198,090 funding given towards this project** - When a person loses their upper body function basic tasks like brushing their teeth, feeding themselves, or hugging family become impossible. Physical barriers and social barriers (assumptions about their role and value in society) restrict freedom.

Eventually, the barriers become insurmountable, removing the ability to live independently, continue in education, secure a job, or sustain a social life. A third of pupils aged 11-15 with a long-term illness, disability or medical condition said their disability negatively impacted their ability to participate in education.

Ultimately, they're removed from public life and become invisible, so too do their voice and needs. This must change. The ELEVEX Suit will give back what Duchenne steals from young people by restoring the use of their arms, the suit will transform disabled kids into independent teenagers living with dignity. It will transform their lives by ultimately delivering a measurable impact on inclusion, educational attainment, and participation in society at large. We are collaborating with Duchenne UK on this project, which is designed not just to benefit the UK, but worldwide, as well as other disease areas and conditions with loss of upper body function.

A dynamic and collaborative team are working on this project, comprising engineers, biomechanics experts, and control system specialists. Crucially, young people from the Duchenne and Spinal Muscular Atrophy communities have joined the design team and have actively shaped the latest concept development work, building on learning from previous prototypes. In 2025, user-centred product testing of several prototypes was conducted in the real world, and we are now at a stage where most of the key engineering challenges have been resolved. The next stage is to complete development of the final features of the mechanical architecture as well as the design. Following completion, the project will move into clinical evaluation, complete medical device certification and define the manufacturing process, aiming to ensure access to users as soon as possible.

We are extremely grateful to our wonderful supporters and to The Brothers Trust for their contributions towards this project, and at time of writing this report we can confirm further funding will be given in 2026.

• **Developing nutritional guidelines, resources and a structured nutritional programme - £50,865 given towards this project -** Obesity is a serious health complication in Duchenne, with negative implications on cardiac and respiratory function, mental health, and quality of life. Numerous factors contribute to weight gain, including limited physical activity and the use of long-term steroids. Whilst the need for better diet and nutritional management in boys with Duchenne is recognised, this aspect of care is not addressed in the NHS, due to lack of resources and specific guidance. The solution is to develop the evidence required to affect change in Duchenne weight management care and a range of resources, tailored to the needs of boys with Duchenne and their families, that they can access particularly after initiation of steroid treatment.

There is currently no structured nutritional and weight management guidance available to boys with Duchenne in the UK. A UK wide survey of families of boys showed that for 46% of patients, nutritional issues are not monitored or addressed in the clinic. The survey also highlighted that Duchenne specific nutritional and lifestyle advice is considered essential by these families. The 2018 international standards of care recommend that a registered dietician should assess nutritional status and create a specific nutritional plan, both of which are currently not available to UK patients through the NHS. Taken together, these highlight a major gap in UK care of boys with Duchenne, which we are uniquely placed to help address through DMD Care UK and funding this project. This project is ongoing, and the NutrinD study is up and running and recruiting, with the aim of identifying the caloric needs of both ambulant and non-ambulant boys on steroid therapy.

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Recent activities and achievements - continued

• **DMD Care UK project manager post at University of Newcastle -** DMD Care UK has now successfully opened working groups across all agreed standards of care. Each working group is working towards having published guidelines, endorsed by the relevant professional bodies – cardiac, respiratory, bone and endocrine. Patient and family guides have been produced in parallel with a publication of each clinical guideline and consultation with the Family Focus Group of DMD Care UK. This enables patients and families to better advocate for their care and to bring latest information to the attention of their clinical teams as well as to make informed choices about their care.

• **DMD Hub is a flagship project that has successfully expanded capacity for clinical trials for Duchenne treatments in the UK -** In the first four years of the project, Duchenne UK, and its partner charities (including Alex's Wish) invested £2.7m in the DMD Hub, with an additional £1.6m committed over the next 4 years. The DMD Hub is a collaboration between Duchenne UK, the John Walton Muscular Dystrophy Research Centre (JWMDRC) in Newcastle, and Great Ormond Street Hospital London. It was set up to expand clinical trial capacity and expertise and stop clinical trials being turned away from the UK. The project team developed the Clinical Trial Finder to help patients access information on DMD clinical trials in the UK.

We are pleased to share that since 2016, the DMD Hub has:
• Engaged with 15 companies and 4 Clinical Research Organisations
• Recruited 800 boys onto clinical trials
• Facilitated 57 clinical trials, 28 are currently active, 7 at feasibility stage and 4 in early discussions
• Provided 34 posts to facilitate the day to day and set up of new trials – 72% of these posts have been sustained
• Leveraged £1.3M of funding from other funders and industry to support DMD clinical research

• **Antifibrotic screening platform, University of Newcastle -** A new molecular biology technique which enables us to look inside muscle cells for Duchenne patients. This will help us to understand which treatments are most effective in preventing fibrosis, a process which happens when muscle cells die and are replaced by fatty tissue. Fibrosis can lead to failure of the heart and respiratory muscles, which is the most common cause of death in adults with Duchenne. While gene therapies could be transformative for people living with Duchenne, the progressive nature of the disease limits their impact. Combining gene therapies with drugs that could reduce muscle deterioration, such as anti-fibrotics could help to maximise the effect of these treatments. Anti-fibrotics could also be used to treat patients who are not eligible for gene therapy, and for those in the later stages of the disease. We funded a PhD post for 3 years, which concluded at the end of 2025, during this time the team has selected a short-list of potentially interesting compounds and were studying the effects of selected drugs, more work is ongoing, with results expected soon.

• **A pioneering Pluripotent Stem Cell Therapy 'Altering the muscle environment to influence stem cell behaviour' at The University of Minnesota** is looking at regenerating muscle in Duchenne patients with stem cells. Stem cells are a potentially exciting approach to generate new healthy muscle in patients with Duchenne. The stem cells we are looking at are called human induced pluripotent stem cells (iPSCs). These cells replace the diseased muscle tissue with stem cells that can create healthy myofibers which are able to regenerate. The aim of this project is to produce and test these stem cells to get the preclinical data required to progress to a clinical trial. This project has proved highly successful; this study involves phase 1 human clinical trial testing the safety and tolerability of stem cells which have proven to contribute to skeletal muscle regeneration in dystrophic mice. The team have now opened this study for recruitment and are actively seeking potential study participants.

• **FOR DMD PhD Post – Dr. Michela Guglieri, University of Newcastle –** the funding provided allowed for the analysis of the FOR DMD trial, which was a double, blind, controlled study designed to assess the relative effectiveness and adverse event profiles in Duchenne of the 3 most frequently prescribed corticosteroid regimes (daily prednisone, daily deflazacort and intermittent 10 days on 10 days off). The project led to 4 publications in high impact scientific journals and the key outcomes were:

• Initiating steroids before age 6 improves motor trajectories over 18 months, supporting treatment no later than age 6.
• Daily steroid regimes benefit ambulant (still walking) boys over 6 years old – enhancing motor performance. Older boys often start intermittent regimes to limit side effects like weight gain, but daily dosing may better maintain motor function.

...CONTINUED

Recent activities and achievements - continued

• Boys starting steroids above motor cut-off values show sustained improvement after 18 months, helping predict future motor performance.

Financial Review

Financial Position

Income from donations and fund-raising activities for the year amounted to £348,052 (2024: £285,913). Bank interest received in the year amounted to £1,193 (2024: £1,168). Returns on investment in Reveragen £19,354 (2024: £nil)

Expenditure incurred is as shown on the detailed statement of financial activities and included: expenditure on fund-raising activities which amounted to £53,737 (2024: £49,842).

Overheads include payments for administrative services and the management of events and fundraising activities of £53,560 (2024: £79,555) and other costs relating to promotional materials, Trustee expenses, insurance, bank charges, marketing, bookkeeping, and networking events of £19,352 (2024: £25,744).

Payments towards research and clinical trials amounted to £232,989 (2024: £113,000). Overall, there were net incoming resources for the year of £6,161 (2024: outgoing £18,940).

Reserves Policy

The Charities SORP requires a charity to state the amount and type of financial reserves it holds, and to compare how the level of those reserves matches up to "The level of reserves the trustees feel as appropriate given their plans for the future activities of the charity". Where it falls short, the trustees need to explain what steps they are taking to rectify the situation. In this context, the charity views financial reserves as those held in its unrestricted funds, the balance of funds stood at £69,868 at the year-end (2024: £71,832).

The Trustees establish the appropriate level of unrestricted reserves (over and above those already ring-fenced for plans or known liabilities within restricted and designated Funds) by seeking to ensure that the level of the charity's 'free reserves' meets a chosen benchmark related to the budgeted expenditure for unrestricted activities. The Trustees consider the "free reserves" to be the unrestricted funds not committed or invested in tangible assets. As a result of a full and objective review of its 'free reserves' policy, considering all the risks foreseeable at that point and the charity's approach to their mitigation, the Trustees agreed on 9th February 2023 that £30,000 should be maintained as 'free reserves'. This level has continued to be reviewed for adequacy and robustness to ensure the Charity maintains adequate finances to meet day-to-day operating costs, and we will continue to review this over the coming months. As of 30 June 2025, the Charity's "free reserves" stood at £69,868 (2024: £71,832), resulting in a surplus of £39,868 (2024: surplus of £41,832) when compared with the current benchmark, calculated as £30,000.

Structure, Governance and Management

Governing Document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarentee, as defined by the Companies Act 2006.

Trustee Selection Methods

Trustees will be recruited through recommendations and social media, at our events and through word of mouth. Those expressing an interest will, in the first instance, be met by the Charity Founder, given an overview of the organisation, and encouraged to apply. The Chair and Co-Chair trustees will examine the applications against the most recent skills audit, produce a short list, and invite those on it to submit their references and then attend an interview; the Chair and Co-Chair will conduct the interviews, and make recommendations to the Board. At its next meeting, the Board will review these recommendations, and either ratify or reject. Successful applicants will be asked to complete and sign the declaration of interest form, sign a declaration that they are eligible to serve as a trustee; and agree to the code of conduct. They will then become a trustee of the Board.

Organisational structure

The organisation is a charitable company limited by guarantee, incorporated on 22 June 2012. The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

The body responsible for management of the Charity is the Board of Trustees of Alex's Wish. The Board meets monthly (and at least ten times per year). The charity's constitution is set out in the Articles of Association, and all Trustees have agreed to this. New Trustees are appointed by the existing Board of Trustees. Trustees give up their time freely and no Trustee remuneration was paid in this year. Details of Trustee expenses and related party transactions are disclosed in the accounts. Trustees are required to disclose all relevant interests and to withdraw from decisions where a conflict of interest arises. None of the Trustees have any interests with the pharmaceutical industry.

We regularly review our stated aims, objectives, and activities to ensure we are working toward our stated purposes. We have referred to the guidance contained in the Charity Commission's general guidance on public benefit under the Charities Act 2011 when setting and reviewing our aims and objectives and in planning our future activities. All our charitable activities focus on improving the lives of those with Duchenne Muscular Dystrophy.

Risk management

The Trustees continue to review the major strategic, business, and operational risks which the charity faces and confirm that systems are in place to enable regular reports to be produced so that the necessary steps can be taken to lessen these risks. In assessing risk, the Trustees recognise that some areas of the work require the acceptance and management of risk if the charity is to achieve its objectives.

Reference and Administrative Details

Trustees

Mr R A Copson (appointed 14/03/2025)
Mr C R Everard
Mr A R Hallam
Mrs E J Hallam
Mr S D Jesrani
Mr S G Masters (appointed 08/05/2025)
Ms A L Slack
Mrs A K Iqbal (resigned 30/04/2025)
Mr W Hazlerigg
Miss S Merrill (appointed 26/02/2026)

Charity Number

1148845

Company Number

08116159

Registered Office

21 New Walk
Leicester
LE1 6TE

Independent Examiner

J Petha FCCA
Sturgess Hutchinson
Chartered Certified Accountants
21 New Walk
Leicester
LE1 6TE

Scientific Advisory Board

We work closely with Duchenne UK as their Charity Partner and as such, majority of the projects we fund are co-funded alongside them.

All projects put forward to us for potential funding go through their rigorous Scientific Advisory Board, which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy.

They bring with them a wide range of essential skills and knowledge bases, including scientific, clinical and drug discovery and development. When scientists come forward with their ideas for new research projects, it is this board who apply their experience and expertise to test these ideas, helping refine them, if necessary, in order that we can make informed decisions on funding. We want to fund great science and projects that can improve our knowledge base, treatments that can reach the clinic and improve the lives of people with Duchenne.

Duchenne UK's advisory board consists of:

- Professor Dame Kay Davies
- Dr. John Bourke
- Dr. Dada Pisconti
- Dr. Valeria Ricotti
- Professor Giovanni Baranello
- Professor Jordi Diaz Manera
- Dr. Tina Duong
- Dr. Isabelle Richard
- Dr. Carina Schey
- Professor Francesco Saverio Tedesco
- Dr. Graeme Wilkinson

Alex's Wish would like to thank its Trustees, employees, service providers and supporters for kindly giving their time and expertise to grow the charity.

Other Information

Strategic approach and plans to fulfil our charitable objectives

In the coming year we plan to:

Objective 1: To identify, fund and monitor medical research projects, clinical trials, clinical trial capacity opportunities and new technological advances.

• To receive updates on outcomes for projects funded so we can report on the impact those projects have made to help progress our mission. To report on these via our news feeds on our website, our social media platforms, e-newsletters to our supporters, through local press coverage and at our events.

• Continue to work closely with Duchenne UK as a Charity Partner. To seek out and fund new projects that fit with our mission to conquer Duchenne – to improve and extend the lives of everyone affected. Ensuring that our funds are spent effectively and in the right areas to help bring about the best chances of bringing new treatments to market.

• Increase our level of income generated each year by building relationships with our existing supporters as well as attracting new supporters to our cause.

• Continue to fund projects that will bring about effective treatments, new technologies, improve care standards, and improve clinical trial capacity in the UK for the Duchenne community and aim to give £200,000+ per annum.

Objective 2: To engage with media and our supporters to raise awareness of Duchenne Muscular Dystrophy.

• Attend the annual Horizons Conferences held by Duchenne UK to engage with other parents affected by Duchenne Muscular Dystrophy, as well as keep abreast of latest progress made in the field of Duchenne. To be actively involved in workshops and meetings alongside Duchenne UK that is focussed on improving care standards in the UK.

• Where possible, attend national events and meetings to help lobby MPs and Parliament to bring about new treatments to market as quickly as possible e.g. Vamorolone and Givinostat.

• Issue press releases and submit to the local press in the East Midlands to help raise awareness about the work we are doing and its impact on the local community / the rest of the UK and to help attract new supporters to our cause.

• Continue to send monthly updates to our supporters via e-newsletters, add newsworthy content to our website and regularly post and grow our supporter base across our social media platforms.

• Organise Supporter events including our annual Spring Launch and our Autumn Lunch to keep in touch with our supporters and guests about the vital work that we do, and how they can continue to help us.

• Continue to attend networking events within the region to build new and foster existing relationships and attract new supporters to our cause and arrange 121's with business supporters on how we can collaborate and foster relationships.

• Continue to speak at community and business events where opportunities to arise.

Objective 3: Income Generation through our flagship events, supporter events and fundraising activities.

• Organise and build on our flagship events: Annual Charity Golf Day, Supercars Day, Charity Football Tournament, Charity Grand Prix event, Annual Fundraising Ball and The Big Christmas Give campaign. Our focus is on generating an income and covering costs and providing a fun and enjoyable fundraising experience for our supporters.

• Support other organisations, groups and individuals who have decided to organise their own events in support of our cause, providing resources and time to support them achieve their fundraising goals.

...CONTINUED

Strategic approach and plans to fulfil our charitable objectives - continued

• To attract supporters to take part in the London Marathon, walking and running events, challenge events e.g., zipwire challenges, skydiving, loop the loop aerobic displays, wing walks, and abseil challenges and to raise as much money as they can doing so, by providing them with the tools and encouragement to do so.

• Retain our existing regular giving supporters and develop new initiatives to grow our regular giving supporter base, through our 'Be More Alex' £7 a month regular giving campaign, our Business Community £75 a month regular subscription in exchange for business benefits such as organising local networking events to bring the local business community together.

• Continue to support businesses who donate a percentage of their income to us every single month and look to attract like-minded businesses.

• We aim to work within a 30:70 ratio of cost vs. income received from an event to ensure that 70% of what we raise from our events overall goes directly to fund projects to further our mission. We would like to attract more capital through corporate sponsors to cover most/if not all our event costs to help improve this ratio further. We have been successful in attracting corporate sponsors and will continue to build on those relationships.

• Majority of our income raised has been through hosting our own events. Our aim is to continue working with local businesses to take Alex's Wish on as their chosen charity and organise their own events and consider Alex's Wish as their Charity of the Year. This means that 90%+ of the money they give to us as a Charity goes directly to fund projects to further our mission as they do not incur the expenditure that our own fundraising activities require.

• Continue to work with charitable foundations who have kindly supported our work, as well as other local charitable groups, to source additional income. We are now outsourcing this important work to an expert in this field to help us identify and approach new trusts and foundation opportunities. We have seen success in this field and hope to continue to find more success as we diversify our income streams.

• Form strategic alliances and partnerships with organisations such as local sporting clubs, colleges, schools, and corporate businesses.

• We hope in the future to launch a podcast to further our reach and attract new audiences to our cause.

Statement of Trustees' Responsibilities

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statement unless they are satisfied that they 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 the financial statements the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgments and accounting estimates that are reasonable and prudent; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

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

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.

Small Company Rules

This report has been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

The trustees' report was approved by the board of trustees and signed on its behalf by:



Mrs E J Hallam

Trustee
12/03/2026

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2025.

Responsibilities and Basis of Report

As the charity trustees of the Company (and also its directors for the purposes of company law), you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ("the 2006 Act").

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

Independent Examiner's Statement

Since the Company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of The Association of Chartered Certified Accountants, which is one of the listed bodies.

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

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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



J Petha FCCA

12/03/2026
Sturgess Hutchinson
Chartered Certified Accountants
21 New Walk
Leicester
LE1 6TE

Alex's Wish
Statement of Financial Activities (including Income and Expenditure Account)
For The Year Ended 30 June 2025

	Notes	Unrestricted funds	Restricted funds	2025 Total funds	2024 Unrestricted funds
		£	£	£	£
INCOME AND ENDOWMENTS FROM:					
Donations and legacies	3	78,958	43,125	122,083	37,644
Charitable activities:					
Fundraising activities		225,969	-	225,969	248,269
Investments	4	1,193	-	1,193	1,168
Other	5	19,354	-	19,354	-
		325,474	43,125	368,599	287,081
EXPENDITURE ON:					
Raising funds	6	(2,800)	-	(2,800)	-
Charitable activities:	6				
Expenditure on charitable events		(53,737)	-	(53,737)	(49,842)
Administrative services		(53,560)	-	(53,560)	(79,555)
Support costs		(19,352)	-	(19,352)	(25,744)
Separate material item of expenditure		(197,989)	(35,000)	(232,989)	(113,000)
		(327,438)	(35,000)	(362,438)	(268,141)
NET INCOME		(1,964)	8,125	6,161	18,940
NET MOVEMENT IN FUNDS		(1,964)	8,125	6,161	18,940
RECONCILIATION OF FUNDS:					
Total funds brought forward		71,832	-	71,832	52,892
TOTAL FUNDS CARRIED FORWARD	14	69,868	8,125	77,993	71,832

The notes on pages 21 to 26 form part of these financial statements.

Alex's Wish
Balance Sheet
As At 30 June 2025

	Notes	Unrestricted funds	Restricted funds	2025 Total funds	2024 Total funds
		£	£	£	£
CURRENT ASSETS					
Debtors	11	20,639	-	20,639	16,083
Cash at bank and in hand		68,857	8,125	76,982	68,138
		89,496	8,125	97,621	84,221
Creditors: Amounts Falling Due Within One Year	12	(19,628)	-	(19,628)	(12,389)
NET CURRENT ASSETS (LIABILITIES)		69,868	8,125	77,993	71,832
TOTAL ASSETS LESS CURRENT LIABILITIES		69,868	8,125	77,993	71,832
NET ASSETS		69,868	8,125	77,993	71,832
FUNDS OF THE CHARITY					
Restricted Funds				8,125	-
Unrestricted Funds				69,868	71,832
TOTAL FUNDS	14			77,993	71,832

For the year ending 30 June 2025 the charitable company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

The members have not required the charitable company to obtain an audit in accordance with section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

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

On behalf of the board



Mrs E J Hallam

Trustee
12/03/2026

The notes on pages 21 to 26 form part of these financial statements.

1. General Information

Alex's Wish is a company limited by guarantee, incorporated in England & Wales, registered number 08116159 and registered charity number 1148845. The registered office is 21 New Walk, Leicester, LE1 6TE.

2. Accounting Policies

2.1. Basis of Preparation of Financial Statements

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) "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)", Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Companies Act 2006.

The charitable company is a Public Benefit Entity as defined by FRS 102.

2.2. Incoming Resources

All income is recognised in the statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

2.3. Resources Expended

Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefit will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruls basis and has been classified under headings that aggregate all cost relating to that category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

2.4. Leasing and Hire Purchase Contracts

Rentals applicable to operating leases where substantially all of the benefits and risks of ownership remain with the lessor are charged to the statement of financial activities as incurred.

2.5. Cash and Cash Equivalents

Cash and cash equivalents are basic financial assets and include cash in hand and deposits held at call with banks, other short-term highly liquid investments that mature in no more than three months from the date of acquisition and are readily convertible to a known amount of cash with insignificant risk of change in value, and bank overdrafts.

2.6. Taxation

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

2.7. Pensions

The charitable company operates a defined pension contribution scheme. Contributions are charged to the Statement of Financial Activities as they become payable in accordance with the rules of the scheme.

3. Income from Donations and Legacies

	Unrestricted funds £	Restricted funds £	2025 Total funds £
Donations and gifts	78,958	-	78,958
Grants	-	43,125	43,125
	78,958	43,125	122,083

	Unrestricted funds £	Restricted funds £	2024 Total funds £
Donations and gifts	37,644	-	37,644
Grants	-	-	-
	37,644	-	37,644

4. Investment Income

	2025 Unrestricted funds £	2024 Unrestricted funds £
Bank interest receivable	1,193	1,168

5. Other Income

	2025 Unrestricted funds £	2024 Unrestricted funds £
Royalty, licence and similar receivables	19,354	-

6. Analysis of Expenditure

	Activities undertaken directly	Support costs (see note 7)	2025 Total
	£	£	£
Raising funds	2,800	-	2,800
Expenditure on charitable events	53,737	-	53,737
Administrative services	-	53,560	53,560
Support costs	-	19,352	19,352
	56,537	72,912	129,449

	Activities undertaken directly	Support costs (see note 7)	2024 Total
	£	£	£
Expenditure on charitable events	49,842	-	49,842
Administrative services	-	79,555	79,555
Support costs	-	25,744	25,744
	49,842	105,299	155,141

7. Support Costs

	Administrative services	Support costs	2025 Total
	£	£	£
Employee costs	53,560	1,848	55,408
Premises expenses	-	1,945	1,945
General administration	-	15,559	15,559
	53,560	19,352	72,912

	Administrative services	Support costs	2024 Total
	£	£	£
Employee costs	79,555	2,841	82,396
Premises expenses	-	7,140	7,140
General administration	-	15,763	15,763
	79,555	25,744	105,299

8. Independent Examiner's Remuneration

	2025	2024
	£	£
Independent examination of the financial statements	2,340	2,340
Other assurance services	-	-
Tax advisory services	-	-
Other financial services	-	-
	2,340	2,340

9. Staff Costs

Staff costs were as follows:

	2025	2024
	£	£
Wages and salaries	52,357	77,943
Other pension costs	1,203	1,612
	53,560	79,555

No employees received employee benefits (excluding employer pension costs) for the reporting period of more than £60,000.

10. Average Number of Employees

Average number of employees during the year was: 2 (2024: 3)

11. Debtors

	2025	2024
	£	£
Due within one year		
Trade debtors	9,265	2,165
Other debtors	11,374	13,918
	20,639	16,083

12. Creditors: Amounts Falling Due Within One Year

	2025	2024
	£	£
Trade creditors	(1)	-
Other creditors	-	409
Accruals and deferred income	19,629	11,980
	19,628	12,389

13. Pension Commitments

The charitable company operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the charitable company in an independently administered fund.

During the year the charge to the statement of financial activities in respect of defined contribution schemes was £1,203 (2024: £1,612).

At the balance sheet date contributions of £0 (2024: £409) were due to the fund and are included in creditors.

14. Movement in Funds

	As at 1 July 2024	Income	Expenditure	As at 30 June 2025
	£	£	£	£
Unrestricted funds				
General:				
General unrestricted fund	71,832	325,474	(327,438)	69,868
Restricted funds				
The Brothers Trust	-	35,000	(35,000)	-
The D'Oyly Carte Charitable Trust	-	6,125	-	6,125
The Hospital Saturday Fund	-	2,000	-	2,000
Total restricted funds	-	43,125	(35,000)	8,125
Total funds	71,832	368,599	(362,438)	77,993

	As at 1 July 2023	Income	Expenditure	As at 30 June 2024
	£	£	£	£
Unrestricted funds				
General:				
General unrestricted fund	52,892	287,081	(268,141)	71,832
Total funds	52,892	287,081	(268,141)	71,832

15. Transactions with Trustees

During the year the expenses reimbursed to the trustees or paid directly to third parties were as follows:

	2025	2024
	£	£
Travel	930	1,367

16. Related Party Disclosures

There have been no related party transaction in the reporting period that require disclosure, except for those disclosed in the Transactions with Trustees note.

17. Company limited by guarantee

The company is limited by guarantee and has no share capital.

Every member of the company undertakes to contribute to the assets of the company, in the event of a winding up, such an amount as may be required not exceeding £1.

	2025 Total funds £	2024 Total funds £
INCOME AND ENDOWMENTS FROM:		
Donations and legacies		
Donations and gifts	78,958	37,644
Grants	43,125	-
	122,083	37,644
Charitable Activities:		
Fundraising activities		
Fundraising activities	225,969	248,269
	225,969	248,269
Investments		
Bank interest receivable	1,193	1,168
	1,193	1,168
Other		
Royalties and similar receivables	19,354	-
	19,354	-
	368,599	287,081
EXPENDITURE ON:		
Raising funds		
Trusts and foundations	(2,800)	-
	(2,800)	-
Charitable Activities:		
Expenditure on charitable events		
Annual Golf Day	(5,960)	(4,794)
Annual Fundraising Ball	(17,539)	(26,199)
Our Business Community	(164)	(355)
London Marathon	(480)	(2,592)
Supercars Charity Event	(7,262)	(4,778)
'Be More Alex' regular giving campaign	(530)	(481)
Abseil Charity Event	(1,059)	(1,272)
AGM / Annual Supporters Thank You Lunch	(3,406)	(3,774)
Miss Great Britain Finals Event	(568)	(1,025)
Football Event	(1,132)	(1,088)
Loop the Loop Challenge with AeroSparx	-	(1,153)
Other sundry event costs	(408)	-
Big Give Christmas Challenge	-	(60)
Fashion Show	(163)	-

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Spring Launch	(31)	(1,247)
Grand Prix Event	(93)	(110)
Kazoo Pink Ball	-	(914)
Wing Walk	(4,888)	-
Flat Gin Run	(12)	-
London to Paris Charity Bike Ride	(7,684)	-
Owning It - 'The Power of Resilience' talks	(2,358)	-
	(53,737)	(49,842)
Administrative services		
Wages	(52,357)	(77,943)
Employers pensions	(1,203)	(1,612)
	(53,560)	(79,555)
Support costs		
Staff training and welfare	(783)	(995)
Travel and subsistence	(1,065)	(1,846)
Rent	(1,945)	(7,140)
Computer software, consumables and maintenance	(3,921)	(3,690)
Office equipment	(35)	(713)
Insurance	(636)	(864)
Postage and stationery	(1,028)	(1,349)
Business development and networking events	(1,519)	(2,063)
Promotional materials	(4,662)	(2,793)
Website and email marketing	(646)	(874)
Independent examiner's fees	(2,340)	(2,340)
Business services	(72)	(450)
Bookkeeping and legal fees	(374)	(257)
Bank charges	(326)	(370)
	(19,352)	(25,744)
Separate material item of expenditure		
Payments for medical research, clinical posts and new technologies	(232,989)	(113,000)
	(232,989)	(113,000)
	(362,438)	(268,141)
NET INCOME	6,161	18,940

ALEX'S WISH

England & Wales - Charity number 1148845

Accounts

REGISTERED COMPANY NUMBER: 08116159 (England and Wales)
REGISTERED CHARITY NUMBER: 1148845

TRUSTEES' REPORT AND

UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2024

FOR

ALEX'S WISH
(A COMPANY LIMITED BY GUARANTEE)

Sturgess Hutchinson
Chartered Certified Accountants
21 New Walk
Leicester
LE1 6TE

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FOR THE YEAR ENDED 30 JUNE 2024

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ALEX'S WISH

REFERENCE AND ADMINISTRATIVE DETAILS
FOR THE YEAR ENDED 30 JUNE 2024

Trustees	Ms S L Barnett (resigned 17/6/2024) Mr T W Carter (resigned 1/10/2023) Ms J Edwards (resigned 17/6/2024) Mr C R Everard Mrs E J Hallam Mr A R Hallam Ms A L Slack Mr S Jesrani Ms G Wright Ms A K Iqbal (appointed 1/4/2024) Mr W Hazlerigg (appointed 9/2/2024)
Registered office	21 New Walk Leicester LE1 6TE
Registered company number	08116159 (England and Wales)
Registered charity number	1148845
Independent examiner	Sturgess Hutchinson Chartered Certified Accountants 21 New Walk Leicester LE1 6TE
Website	www.alexswish.co.uk
Bankers	National Westminster Bank 5 The Parade Oadby Leicester LE2 5NT

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2024

The Trustees, who are also Directors of the charitable company for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 30 June 2024. The trustees have adopted the provisions of 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).

Scientific Advisory Board
We work closely with Duchenne UK as their Charity Partner and as such, most projects that we fund are co-funded alongside them.

All projects put forward to us for potential funding go through their rigorous Scientific Advisory Board, which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy.

They bring with them a wide range of essential skills and knowledge bases, including scientific, clinical and drug discovery and development. When scientists come forward with their ideas for new research projects, it is this board who apply their experience and expertise to test these ideas, helping refine them, if necessary, in order that we can make informed decisions on funding. We want to fund great science and projects that can improve our knowledge base, treatments that can reach the clinic and improve the lives of people with Duchenne.

Duchenne UK's advisory board consists of:

Professor Dame Kay Davies
Dr. John Bourke
Dr. Dada Pisconti
Dr. Valeria Ricotti
Professor Giovanni Baranello
Professor Jordi Diaz Manera
Dr. Tina Duong
Dr. Isabelle Richard
Dr. Carina Schey
Professor Francesco Saverio Tedesco
Dr. Graeme Wilkinson

Alex's Wish would like to thank its Trustees, employees, service providers and supporters for kindly giving their time and expertise to grow the charity.

Statement from the CEO and Charity Founder, Emma Hallam

Since we launched Alex's Wish in late 2012, after our son Alex was diagnosed with Duchenne Muscular Dystrophy - we have made great progress towards bringing effective new treatments to help everyone affected by this disease, as well as helping to improve care standards across the UK - whilst also supporting new technological advances to help improve quality of life for everyone living with Duchenne.

We would like to thank everyone who has supported us to date, we could not do what we do with out you. Thank you from the bottom of my heart.

Background to setting up Alex's Wish
Duchenne is a life-changer. It affects every single day of your life as you must be prepared for ever-changing challenges that affect your child's/young adult's day to day activities. Duchenne is a progressive, muscle wasting disease. It is relentless, affecting every single muscle in the body. One day your child may not be able to walk, may not be able to lift a cup to their mouth, may not be able to access their friends' homes anymore. We felt overwhelmed and terrified of what the future held for our son, living in fear of the next stage of progression and wondered how we would cope.

At the time of diagnosis, we quickly realised we had no time to waste, and that funding was the main cause of concern. So, we set-up Alex's Wish, a charity based in the heart of Leicestershire, as we knew we would attract interest and support from the community across the East Midlands and beyond, bringing in additional funds to what was already being raised. We do not duplicate efforts of other charities working in this field, instead our focus is to drive additional funds, allowing us to co-fund projects with other charities like Duchenne UK.

An exciting time in medical breakthroughs
The science is at a very exciting time; a time of optimism as new treatments are now emerging to delay disease progression. We are acutely aware that time is not on our side, and that for families affected by Duchenne - whether they have a child diagnosed several years ago, or new families receiving a recent diagnosis - need solutions to support their child. This is what drives us every single day, to fundraise and raise awareness to continue supporting new innovative projects to address the problems within the Duchenne community.

Vamorolone
In 2023, we saw a breakthrough - the first ever drug approved for use on children with Duchenne - called Vamorolone. It is reaching patients because charities like ours help to fund the early stages of the project. When Alex was diagnosed back in 2010, we were told the standard medication for children with Duchenne, steroids, would keep them independently mobile for longer, but with harmful side effects.

The research we have funded is now bearing fruit. Vamorolone a new steroid drug, that has less harmful side-effects to traditional steroids, has now been approved by the Medicines and Healthcare products Regulatory Agency (MHRA) in the UK. We are incredibly proud that we were able to invest in the early stages to make this a reality - proof that Alex's Wish is a charity that is making a positive impact for this generation of children and young adults living with Duchenne.

Gene Therapy
We were told that Gene Therapy wouldn't happen in our son's lifetime. During the time that Alex's Wish has been in operation, we supported Solid Biosciences, a start-up to pursue this new technology, and boys are now being dosed with gene therapy in clinical trials taking place now in the UK. We know there are challenges with Gene Therapy, which is why we are continuing support projects that are looking to address these problems - and bring better therapies to our children.

Innovative technologies
Supporting Duchenne UK, we are helping drive technological advances for the benefit of children and young adults living with Duchenne. We are supporting a project to help develop the first ever arm assist device (called ELEVEX) to support arm function. It is a project that puts the needs and aspirations of Duchenne children at its heart, with the potential to bring benefit to other people with arm mobility issues. In addition, we are supporting The DREAM Wheelchair project - again working alongside Duchenne UK. These projects aim to bring better quality of life to everyone affected by Duchenne - and we are excited with the progress being made.

Best practice in Duchenne care
We are working alongside DMD Care UK, to help support better quality of care for everyone living with Duchenne in the UK. To date, we have funded projects, including financial support for a DMD Hub Project Manager designed to increase clinical trial capacity in the UK, a nutrition programme supporting those affected by Duchenne, and a research project looking to address the lack of accessible housing amongst our community. At the time of writing this report, we have funded additional care projects - including a transition project, to help those transitioning from paediatric care into adulthood - something which we have recently encountered ourselves with Alex.

With all this progress, we cannot help but feel incredibly optimistic that more effective treatments will emerge, and new innovative technologies will become available alongside improved care standards to help everyone living with Duchenne. The hard work is paying off, but we must continue our journey and fund the projects we've already invested in to get those to the next stages, as well as find new discoveries to slow down and ultimately stop muscle wasting. Our mission is not only to eradicate Duchenne, but to slow down the disease and help those living with Duchenne live the best lives possible with new technologies and improved standards of care.

We are delighted with our progress to date and excited about the times ahead. We are incredibly grateful to our wonderful supporters who have come on this journey with us so far.

We are incredibly positive about the future and Alex's Wish gives us hope. Duchenne Muscular Dystrophy is part of our lives, not out of choice, but we will make it as best as we can, and we will never stop our journey to conquering Duchenne.

I continue to support to this important cause, by working voluntarily for the charity and a very proud trustee and CEO - it is my pleasure to do this, to support all families affected by Duchenne.

We could not have done our work without our army of supporters, the charitable foundations who have supported us, the local business community, our business sponsors, our fundraising team, ambassadors and our dedicated trustees and we would like to express our gratitude and thanks to every single one of them.

Best wishes,

Emma Hallam
Charity Founder

Our Vision
Our Vision is a world without Duchenne Muscular Dystrophy.

We want a future that stops the devastating impact Duchenne has on our children and young adults, a future where they can grow and prosper and fulfil their dreams.

A life where they can enjoy every day without the fear of the progression this muscle wasting disease has on their bodies.

A future without Duchenne would be a bright and happy future for all those affected.

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2024

We need to act quickly to save this generation. Doing nothing is not an option. Our boys and their families need to live without fear and have hope for the future.

Our Mission
Alex's Wish has one clear aim - to conquer Duchenne for this generation. Together we will end Duchenne.

Our ultimate focus is to extend the lives of those living with Duchenne right now, to halt and ultimately reverse the effects of muscle wasting. Whilst also supporting the delivery of excellent standards of care and new technologies to help improve the lives of those affected in the UK.

Alex's Wish was set-up by a family affected by Duchenne, who understand first-hand the impact this condition has on their child and the family. As a family we are taking part in clinical trials ourselves as we understand the importance of clinical trials and how they will help bring effective treatments to market.

Alex, who inspired us to create this charity, has spent 11 years of his life so far on clinical trials, and has helped in his way to bring about a new treatment called Givinostat to market - a drug that is proven to delay disease progression in Duchenne. We are so proud of the efforts he puts in to support our fundraising activities.

Charities like ours fund half of all medical research in the UK to the tune of £1.7bn. Today, 1 in 4 people choose to support medical research charities like ours, and for this we are so incredibly grateful.

Our Impact
The Trustees are delighted that they have been able to make significant payments during this accountancy period to two projects equating to £113,000 in line with its objectives. We provide project updates as and when they become available on our website alexswish.co.uk, e-newsletters to our supporters and at our events - namely our Autumn Lunch and Spring Launch events.

Given an additional sum of £50,000 towards the ongoing work of The ELEVEX Suit (previously known as The Smart Suit and The Arm Assist Suit).

When a person loses their upper body function basic tasks like brushing their teeth, feeding themselves, or hugging family become impossible. Physical barriers and social barriers (assumptions about their role and value in society) restrict freedom.

Eventually, the barriers become insurmountable, removing the ability to live independently, continue in education, secure a job, or sustain a social life. A third of pupils aged 11-15 with a long-term illness, disability or medical condition said their disability negatively impacted their ability to participate in education.

Ultimately, they're removed from public life and become invisible, so too do their voice and needs. This must change. The ELEVEX Suit will give back what Duchenne steals from young people by restoring the use of their arms, the suit will transform disabled kids into independent teenagers living with dignity. It will transform their lives by ultimately delivering a measurable impact on inclusion, educational attainment, and participation in society at large. We are collaborating with Duchenne UK on this project, which is designed not just to benefit the UK, but worldwide, as well as other disease areas and conditions with loss of upper body function.

A dynamic and collaborative team are working on this project, comprising engineers, biomechanics experts, and control system specialists. Crucially, young people from the Duchenne and SMA communities have joined the design team and have actively shaped the latest concept development work, building on learning from previous prototypes.

We are extremely grateful to our wonderful supporters and to The Brothers Trust for their contribution towards this project.

Given £63,000 towards the 'Help the Heart' Cardiac Grant Call.

Our heart muscles need dystrophy to function efficiently. In Duchenne, a lack of dystrophin means that heart muscles weaken over time. Heart cells are replaced by scar and fatty tissue, which leads to a type of heart muscle disease called dilated cardiomyopathy. The age when this happens in Duchenne can vary from person to person, from early childhood to adulthood.

Children with Duchenne don't usually have cardiac symptoms. However, weakening heart muscles are part of the natural progression of the disease. Therefore, early monitoring, preventative treatment, and ongoing management are important for keeping the heart healthy into adulthood. It is currently not possible to prevent heart weakness in Duchenne completely. However, steroids and heart medication can slow down the decline in heart function.

This grant call will help us understand how the heart is affected and identify potential innovative treatment strategies and approaches. In response to a huge unmet need in cardiac management and effective therapeutic options targeted to at the heart, leading to poor outcomes in people living with Duchenne, this will area of focus for us in 2024 and 2025 and thrilled to share that two cardiac projects are now pushing forward. One in repurposing Empagliflozin for DMD and the other an international survey on clinical presentation and service provision to inform ongoing care.

In addition to these projects, we have several other active projects that we have previously supported pushing forward this year. As well as pledged support to various projects in the latter half of 2024 and 2025.

We have continued to raise awareness about Duchenne Muscular Dystrophy.
Through regular posting across our social media platforms, about stories, progress, medical news, ways in which our supporter make an impact and how they can support us on the future and are seeing an ever increasing following and engagement online.

Thank you to everyone who follows our journey. Through our calendar of events, we have been raising the profile of our cause and engaging with existing and new supporters.

We have secured a pipeline of fundraising support and activities over the next 12 months.
In addition to the funds received during this financial year, we have seen great success with our fundraising activities in the latter part of 2024 and into 2025.

We have secured funding from various trusts and foundations, including The Brothers Trust.

Delivered a calendar of successful and profitable fundraising activities and events for our supporters to get involved with, so that we can continue to raise money to further our mission.

We have secured funding from local high-profile events - such as The Nottingham Hot Property Show.

We have been working with NEXT Plc to develop Alex's Wish inspired children's pyjamas to raise money for our cause.

Plus, much more, you can find out more by following us across our social media platforms and on our website.

Recent activities and achievements
Over the years, we have funded a variety of projects across a broad-spectrum from early-stage research through to clinical trials, funded five clinical posts to support clinical trial development and patient access, funded DMD Care projects, as well as invested in new technologies.

Here are some examples of the work we have funded over recent years.

Developing nutritional guidelines, resources and a structured nutritional programme
Obesity is a serious health complication in Duchenne, with negative implications on cardiac and respiratory function, mental health, and quality of life. Numerous factors contribute to weight gain, including limited physical activity and the use of long-term steroids. Whilst the need for better diet and nutritional management in boys with Duchenne is recognised, this aspect of care is not addressed in the NHS, due to lack of resources and specific guidance. The solution is to develop the evidence required to affect change in Duchenne weight management care and a range of resources, tailored to the needs of boys with Duchenne and their families, that they can access particularly after initiation of steroid treatment.

There is currently no structured nutritional and weight management guidance available to boys with Duchenne in the UK. A UK wide survey of families of boys showed that for 46% of patients, nutritional issues are not monitored or addressed in the clinic. The survey also highlighted that Duchenne specific nutritional and lifestyle advice is considered essential by these families. The 2018 international standards of care recommend that a registered dietician should assess nutritional status and create a specific nutritional plan, both of which are currently not available to UK patients through the NHS. Taken together, these highlight a major gap in UK care of boys with Duchenne, which we are uniquely placed to help address through DMD Care UK and funding this project. This project is ongoing, and clinical recommendations are expected in 2025.

DMD Care UK project manager post at University of Newcastle - DMD Care UK has now successfully opened working groups across all agreed standards of care - now 13 in total. Each working group is working towards having published guidelines, endorsed by the relevant professional bodies - cardiac, respiratory, bone and endocrine. Patient and family guides have been produced in parallel with a publication of each clinical guideline and consultation with the Family Focus Group of DMD Care UK.

This enables patients and families to better advocate for their care and to bring latest information to the attention of their clinical teams as well as to make informed choices about their care.

DMD Hub is a flagship project that has successfully expanded capacity for clinical trials for Duchenne treatments in the UK. In the first four years of the project, Duchenne UK, and its partner charities (including Alex's Wish) invested £2.7m in the DMD Hub, with an additional £1.6m committed over the next 4 years. The DMD Hub is a collaboration between Duchenne UK, the John Walton Muscular Dystrophy Research Centre (JWMDRC) in Newcastle, and Great Ormond Street Hospital London. It was set up to expand clinical trial capacity and expertise and stop clinical trials being turned away from the UK. The project team developed the Clinical Trial Finder to help patients access information on DMD clinical trials in the UK.

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2024

We are pleased to share that since 2016, the DMD Hub has:
Engaged with 16+ companies and 5 Clinical Research Organisations
Recruited 793 boys on DMD trials
Facilitated 57 clinical trials, 28 are currently active, 7 at feasibility stage and 4 in early discussions
Provided 34 posts to facilitate the day to day and set up of new trials - 72% of these posts have been sustained Leveraged £1.3M of funding from other funders and industry to support DMD clinical research

Antifibrotic screening platform, University of Newcastle - a new molecular biology technique which enables us to look inside muscle cells for Duchenne patients. This will help us to understand which treatments are most effective in preventing fibrosis, a process which happens when muscle cells die and are replaced by fatty tissue. Fibrosis can lead to failure of the heart and respiratory muscles, which is the most common cause of death in adults with Duchenne. While gene therapies could be transformative for people living with Duchenne, the progressive nature of the disease limits their impact. Combining gene therapies with drugs that could reduce muscle deterioration, such as anti-fibrotics could help to maximise the effect of these treatments. Anti-fibrotics could also be used to treat patients who are not eligible for gene therapy, and for those in the later stages of the disease. We funded a PhD post who was successfully appointed in August 2022 and substantial progress has been made.

MyoGene Bio - a company developing cutting edge therapies for muscle diseases. MyoGene has further advanced preclinical development of a gene editing therapy for Duchenne with a mutation in 45-55. The experiments in dystrophic mice have been completed and they will be moving on to a large animal model study. This could be the first gene editing therapy for Duchenne reaching the clinic and are excited to see next steps.

Lipid Nanoparticles (LNPs) technology used in COVID-19 vaccine to see whether it could be used to help in gene therapy treatments for Duchenne - Leiden University Medical Centre. Lipids are naturally occurring small fatty molecules that exist within the body, and nanoparticles refers to their small size. LNPs are currently being used as a key component in the Pfizer/BioNTech and Moderna COVID-19 vaccine.

Several clinical trials of gene therapy are now underway in Duchenne using harmless viruses, called AAVs, to deliver synthetic gene to replace the faulty dystrophin gene in Duchenne. The early data looks promising. But there are some challenges in getting this treatment to the entire Duchenne population, mainly because some patients will have pre-existing antibodies to the virus and so will not currently be able to have the treatment. There are also difficulties in transferring the genes from the viruses into muscle cells. This study aimed to address some of these challenges by exploring LNPs as a method of delivering gene therapy. The findings were inconclusive; however, the research team are continuing their investigations for potential future success in treatment Duchenne.

A pioneering Pluripotent Stem Cell Therapy 'Altering the muscle environment to influence stem cell behaviour' at The University of Minnesota is looking at regenerating muscle in Duchenne patients with stem cells. Stem cells are a potentially exciting approach to generate new healthy muscle in patients with Duchenne. The stem cells we are looking at are called human induced pluripotent stem cells (iPSCs). These cells replace the diseased muscle tissue with stem cells that can create healthy myofibers which are able to regenerate. The aim of this project is to produce and test these stem cells to get the preclinical data required to progress to a clinical trial. This project has proved highly successful, this study involves phase 1 human clinical trial testing the safety and tolerability of stem cells which have proven to contribute to skeletal muscle regeneration in dystrophic mice. A clinical trial recruitment is expected in 2025.

FOR DMD PhD Post - Dr. Michela Guglieri, University of Newcastle - the funding provided allowed for the analysis of the FOR DMD trial, which was a double, blind, controlled study designed to assess the relative effectiveness and adverse event profiles in Duchenne of the 3 most frequently prescribed corticosteroid regimes (daily prednisone, daily deflazacort and intermittent 10 days on 10 days off). The project led to 4 publications in high impact scientific journals and the key outcomes were:

Initiating steroids before age 6 improves motor trajectories over 18 months, supporting treatment no later than age 6. Daily steroid regimes benefit ambulant (still walking) boys over 6 years old - enhancing motor performance. Older boys often start intermittent regimes to limit side effects like weight gain, but daily dosing may better maintain motor function.
Boys starting steroids above motor cut-off values show sustained improvement after 18 months, helping predict future motor performance.

We supported the IGNITE DMD (SGT-001) Gene Therapy programme with Solid Biosciences - we were told gene therapy would not happen in our lifetimes. But we did not accept that. We are pleased to say this gene therapy programme has been tested in clinic in the US. Gene therapy offers hope as a potential treatment for Duchenne. We are extremely proud to have played a part in helping to accelerate the development of gene therapy.

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2024

Objectives and activities
Charitable Objectives and Activities

1. The principal objects of the charitable company are the relief of sickness and the preservation of good health by supporting scientific research into the improved diagnosis, prevention, or treatment of Duchenne Muscular Dystrophy by:

a) Extending the current scope of drugs / treatments so that they will help all children with Duchenne Muscular Dystrophy.
b) Fund first stage clinical trials that provide the safety and efficacy of some of these treatments and then progress this into larger scale production.
c) Fund the completion of scientific work already begun, to bring it to clinical trials, and fund other forms of treatment that will work on all children regardless of their genetic mutation.
d) Fund studies that will bring about data and information to help decision makers make decisions on which treatments to bring to market.
e) Fund the DMD Care programme empowering patients/families to access the best care wherever they live in the UK.
f) Fund new technological advances to help children and young adults living with Duchenne live a better quality of life.

2. Advance the education of the general public in all areas relating to Duchenne Muscular Dystrophy by disseminating information on the disease and its treatments and cures. To:

a) Disseminate information using online and offline materials, including the Alex's Wish Website and via our monthly e-newsletters to our supporters.
b) Running events and fundraising activities, including our Spring Launch and Autumn Lunch which sees our team, trustees, representatives from Duchenne UK, and our supporters come together for us to share our impact during the last 12 months and our plans.
c) Promoting our work across a variety of social media platforms, including Facebook, You Tube, Linked in, Instagram and Tik Tok.
d) We have built great relationships with the local media outlets in our region including ITV Central and BBC East Midlands and regularly generate news articles and updates in local newspapers, including The Leicester Mercury, The Loughborough Echo and local magazines posted through doors. We appear regularly on the local radio stations including BBC Radio Leicester to raise awareness about Duchenne and the impact this has on families living with it.
e) Talking and presenting at various events on Corporate Social Responsibility, the impact of living with Duchenne Muscular Dystrophy and About Alex's Wish - it is important our personal story is shared amongst others to be the voice for other families affected by Duchenne.
f) Participate in alliances and liaise with the Government to inform policy makers and other stakeholders about the work of the charity, the nature of the disease and potential treatments and cures.

Our Grantmaking Policy and Collaboration

The Charity has established its grant making policy to achieve its objectives for the public benefit to find a cure for Duchenne Muscular Dystrophy and to slow down the rate of progression by maintaining muscle strength for longer leading to increase life expectancy as well as a better quality of life.

We only want to fund great science - projects that can improve the knowledge base and bring treatments that can reach the clinic and improve the lives of boys with Duchenne Muscular Dystrophy in many ways. We want to fund new technologies that will go on to help those affected by Duchenne, by making the world accessible to them.

We formed a partnership with Duchenne UK. Duchenne UK share the same mission and objectives as Alex's Wish and are also a parent-led charity. As a Charity Partner to Duchenne UK, we receive projects that require co-funding. All such projects have been reviewed extensively by their Scientific Advisory Board (SAB) which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy. They bring with them a wide range of essential skills and knowledge basis including scientific, clinical and drug discovery and development. When scientists approach Duchenne UK with their ideas for new research projects it is the SAB who apply their experience and expertise to test these ideas, helping to refine them, if necessary, in order that Duchenne UK can make informed decisions on funding. Alex's Wish Trustees review all projects put forward before deciding upon specific projects to fund.

Dr. Alessandra Gaeta, Director of Research and Development at Duchenne UK says 'I feel very proud of what we have achieved, with Alex's Wish invaluable support. We are committed to identify and fund the best projects that can transform DMD treatment and care, to achieve better outcomes for all people living with Duchenne'.

We regularly send updates on project performance and outcomes to our supporters through a monthly e-newsletter as well as publish updates on our social media channels, news articles on our website and submit press releases to the local media companies. We have appeared on BBC East Midlands Today and ITV Central.

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2024

Achievement and performance
Our Major Achievements

- Co-funded 36 projects across a broad-spectrum from early-stage research through to clinical trials, funded 5 clinical posts to support clinical trial development and patient access, funding DMD Care projects, as well as invested in new technologies. Here are just a few examples of the work we have funded to date.

- **The Smart Suit revolutionary technology for upper body strength and function** in children living with Duchenne. This Suit - funded by players of People's Postcode Lottery, Duchenne UK, Alex's Wish and Joining Jack - helps disabled people keep the use of their aims. The project officially started in July 2022, and since then the project has developed at a fast pace. Following the research carried out with young people, families, and clinicians at the end of 2023, three new concept visions have been created, and work continues to progress in 2024. We will continue to support this ongoing work.

- **The DREAM Wheelchair** - transforming the lives of young wheelchair users. In 2017, in partnership with Whizz-Kidz, Duchenne UK won a £1million grant to develop a new wheelchair which is now at the working prototype stage. This project will explore all the options on how we can bring the chair to market, which will ultimately improve quality of life for wheelchair users. Alex's Wish gave £40K to the project, with a further £20K provided by St. James's Place Charitable Foundation and an additional £5K by The Brothers Trust. For children and young people living with Duchenne, using a wheelchair makes all the difference to their independence. But, despite huge advances in technology in almost every area of life, design and functionality of wheelchairs has changed little in 15 years. Getting up a kerb, seeing what is behind you, even having somewhere to put your phone - things the rest of us barely notice in our lives - are major tasks for young wheelchair users. The DREAM Wheelchair project is designed to bring wheelchairs into the 21st century, transforming young lives.

- **Gene editing therapy to accelerate the investigations needed to translate stem cell-based approaches or gene therapies into clinical trials or application in patients.** The funding for this project will support testing a gene-editing therapy for Duchenne in preclinical models. This study is making great progress against all aims. Small and large animal studies are now underway.

- **DMD Hub Manager** is a flagship project that has successfully expanded capacity for clinical trials for Duchenne treatments in the UK. In the first four years of the project, Duchenne UK, and its partner charities (including Alex's Wish) invested £2.7m in the DMD Hub, with an additional £1.6m committed over the next 4 years. The DMD Hub is a collaboration between Duchenne UK, the John Walton Muscular Dystrophy Research Centre (JWMDRC) in Newcastle, and Great Ormond Street Hospital London. It was set up to expand clinical trial capacity and expertise and stop clinical trials being turned away from the UK. The project team developed the Clinical Trial Finder to help patients access information on DMD clinical trials in the UK. Thanks to the DMD Hub, to date, more than 574 boys have been recruited since it was established in 2016 to clinical trials who otherwise may not have been. Emma Heslop is the DMD Hub Manager and is key to the success of this project. Working closely with the Duchenne UK team, she ensures patients are appropriately represented as key stakeholders in all aspects of the DMD Hub. As part of the team at the JWMDRC in Newcastle, she has direct access to clinicians and industry partners through the relationships she has cultivated over the years. As the main point of contact for all companies with trials coming to the UK, she also promotes the UK as an attractive place to run DMD trials and works with them to support site selection, set up and patient recruitment.

- **Antifibrotic screening platform** (a new molecular biology technique which enables us to look inside muscle cells for Duchenne patients. This will help us to understand which treatments are most effective in preventing fibrosis, a process which happens when muscle cells die and are replaced by fatty tissue. Fibrosis can lead to failure of the heart and respiratory muscles, which is the most common cause of death in adults with Duchenne. While gene therapies could be transformative for people living with Duchenne, the progressive nature of the disease limits their impact. Combining gene therapies with drugs that could reduce muscle deterioration, such as anti-fibrotics could help to maximise the effect of these treatments. Anti-fibrotics could also be used to treat patients who are not eligible for gene therapy, and for those in the later stages of the disease. We funded a PhD post who was successfully appointed in August 2022 and substantial progress has been made during the first year, the interim report showed that the first aim of characterising the potential cytotoxic effect of the selected drugs in vitro has been completed and treatment proved safe to progress to in vivo studies in mouse models.

- **Lipid Nanoparticles (LNPs) technology used in COVID-19 vaccine to see whether it could be used to help in gene therapy treatments for Duchenne.** Lipids are naturally occurring small fatty molecules that exist within the body, and nanoparticles refers to their small size. LNPs are currently being used as a key component in the Pfizer/BioNTech and Moderna COVID-19 vaccine. Several clinical trials of gene therapy are now underway in Duchenne using harmless viruses, called AAVs, to deliver synthetic gene to replace the faulty dystrophin gene in Duchenne. The early data looks promising. But there are some challenges in getting this treatment to the entire Duchenne population, mainly because some patients will have pre-existing antibodies to the virus and so will not currently be able to have the treatment. There are also difficulties in transferring the genes from the viruses into muscle cells. This study aims to address some of these challenges by exploring LNPs as a method of delivering gene therapy. The study is called 'mRNA Targeted Therapeutics for Duchenne Muscular Dystrophy' and will be led by Professor Shenhav Cohen at Technion Institute of Technology, Israel, in partnership with Professor Aartsma-Rus at Leiden University Medical Center and Professor Peer at Tel Aviv University. LNPs can be filled with a variety of materials, including genetic material. Because LNPs are made of naturally occurring lipids, they should not cause an immune response. They also have a good safety profile for use in humans. This study will explore whether a larger dystrophin construct can be carried by the LNPs. The dystrophin gene is the largest gene in the body, but in current gene therapy trials, a shortened construct must be used. Our current understanding of the impact of shortened dystrophin on long-term muscle function is limited, but using a longer gene could lead to better muscle function. The research group plans to engineer the LNP surface such that the LNP will effectively fuse with muscle and deliver its cargo. This research is currently in very early stages. If the researchers can show that this method can effectively deliver genetic material into muscles using a mouse model of DMD, they would have a high chance of receiving a much larger grant for further research. The 1-year report was received in May 2022, and highlighted the need for an extension, which was granted. The project team successfully completed the preparation of the nanoparticles; however they were delayed in starting the animal studies, which is now underway.

- **We Invested in a pioneering Pluripotent Stem Cell Therapy 'Altering the muscle environment to influence stem cell behaviour' at The University of Minnesota** which is looking at regenerating muscle in Duchenne patients with stem cells. Stem cells are a potentially exciting approach to generate new healthy muscle in patients with Duchenne. The stem cells we are looking at are called human induced pluripotent stem cells (iPSCs). These cells replace the diseased muscle tissue with stem cells that can create healthy myofibers which are able to regenerate. The aim of this project is to produce and test these stem cells to get the preclinical data required to progress to a clinical trial. This project has proved highly successful, and the success of the findings has led to IND-submission and the initiation of a Phase 1 Clinical Trial in 2024.

- **A study that is paving the way for improved detection of heart disease in female carriers of Duchenne with De Lee Borthwick and Dr John Bourke at Newcastle University** - following this investment, we are pleased to say that this project has improved understanding of heart muscle disease in female carriers, paving the way for further research. Women and girls who carry a mutated Duchenne gene (carriers) can sometimes show mild symptoms of the diseases. Duchenne carriers are at risk of developing cardiomyopathy, which affects the ability of the heart to pump blood around the body. Currently Duchenne female carriers are advised to have their hearts checked every 3-5 years by taking scans such as ECG, echocardiogram, or MRI. However, quicker, and more cost-effective ways to detect heart problems would prevent late diagnosis and enable earlier treatment. De Borthwick and Bourke examined the heart tissue of patients and used this to identify molecules in the blood that could act as biomarkers (indicators of damage to the heart). This study has now come to a close, and the preliminary data shows these biomarkers have the potential to detect early cardiomyopathy in a way that is fast, reliable and cost-effective. The biomarkers need to be tested in cohorts of female carriers, as well as male Duchenne patients, to be fully validated. This pilot project has laid vital foundations for future research to improve the speed of diagnosis and treatment of cardiomyopathies.

- **We helped fund a PhD post at The John Walton Muscular Dystrophy Research Centre at Newcastle University** specifically to look at the FOR-DMD Study (finding the optimum Steroid regime for boys living with Duchenne) supervised by Dr Michela Guglieri. The PhD post will ensure that the data generated by the FOR-DMD study will be used to address new clinical and research questions, and well as sharing the results with the community, possibly through a series of webinars in 2024.

- **We are helping improve the success rate of clinical trials (PC Slices)** this project is working with Professor Mann and Dr Borthwick from the Newcastle Fibrosis Research Group in the University Biosciences Institute. We had some devastating news at the end of 2019: the early termination of a clinical trial run by Wave Life Sciences. The news was a big blow, not least because early data in animals had shown that the drug was effectively producing dystrophin. How could a trial that showed such a promise in animal models not deliver results in humans? Early-stage tests are done on mice with Duchenne and then transferred to trials in people - but there is uncertainty whether a drug might behave the same in the human body. We want to stop this. That's why we supported this project, which has the potential to help us understand, at a much earlier stage of research, whether a medicine will help treat Duchenne patients. The project has been hit by a reduction in elective surgeries and heart transplants due to COVID, but some material and analysis was still able to take place during this time. A 12-month no cost extension was granted, to able the PhD student to complete their studies, and interim report was received in June 2022 which showed good progress, and the project has demonstrated the translational advantages and benefits of interrogating disease mechanisms, identifying new therapeutic targets and testing novel compounds in the more translationally relevant human Precision Cut Slice platform.

- **We supported the IGNITE DMD (SGT-001) Gene Therapy programme with Solid Biosciences** - we were told gene therapy would not happen in our lifetimes. But we did not accept that. We are pleased to say this gene therapy programme has been tested in clinic in the US. Gene therapy offers hope as a potential treatment for Duchenne. We are extremely proud to have played a part in helping to accelerate the development of gene therapy. In September 2022, Solid announced that it had made a strategic decision to prioritise SGT-003, their next-generation AAV gene therapy candidate over SGT-001 it's first-generation gene therapy candidate. News in January 2024 announced it has been granted orphan drug designation from the FDA for SGT-003 which now furthers their efforts to meet the ongoing challenge of treating this devastating disease as expeditiously as possible, these designations are important milestones, supporting the continued development of next-generation therapies for Duchenne. Solid is now currently in the process of securing approvals from the institutional review boards (IRB) at the clinical trial sites for the planned Phase 1/2 clinical trial of SGT-003 and expects to commence patient screening shortly thereafter. Patient dosing in the trial is expected to commence in mid-to-late first quarter of 2024.

- **We supported a 5-year period (2015-2020) Lectureship Post (Dr Michela Guglieri)** - and we are delighted to report the outcomes of this grant, which was supported by a consortium of seven UK charities, Alex's Wish joined by Duchenne UK, Action Duchenne, Duchenne Research Fund, Duchenne Now, Duchenne UK, Harrison's Fund and Joining Jack to invest a total of £250,000. The Clinical Trials Lectureship grant enabled Dr Michela Guglieri to act 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 research centres, that ensures trials are run smoothly and safely, and generate good quality data. The project has supported the establishment of a strong clinical research team at the John Walton Muscular Dystrophy Research Centre and of national and international collaborations and networks which will play a key role in ensuring the clinical research in Duchenne Muscular Dystrophy will continue to come to the UK and to establish the UK as an expert and efficient country to deliver best care practice and clinical research. Since May 2017, as well as training and supporting the staff in the clinical research centre, over the course of the grant, Dr Guglieri has led 10 clinical trials in Duchenne, including The FOR DMD Study and The Vision DMD Trial, testing the safety and effectiveness of Vamorolone - a potential drug that researchers hope could offer some of the effects of steroids with fewer side effects. The support from the 7 different charities has not only resulted in significant impact during the years of funding, but also a permanent position for Michela through Newcastle University. In this role, she will continue to work as Clinical Research Lead, supporting clinical research activities as well as national and international collaborations to improve care, treatment and research opportunities for people living with Duchenne muscular dystrophy. https://alexswish.co.uk/support-from-alexs-wish-helps-fund-duchenne-muscular-dystrophy-dmd-clinical-trials-lectureship/

Financial review
Financial Review
Income from donations and fund-raising activities for the year amounted to £285,913 (2023: £343,744). Bank interest received in the year amounted to £1,168 (2023: £834).

Expenditure incurred is as shown on the detailed statement of financial activities and included: expenditure on fund-raising activities which amounted to £49,842 (2023: £51,201).

Overheads include payments for administrative services and the management of events and fundraising activities of £79,555 (2023: £66,419) and other costs relating to promotional materials, Trustee expenses, insurance, bank charges, marketing, bookkeeping, and networking events of £29,115 (2023: £28,033).

Payments towards research and clinical trials amounted to £113,000 (2023: £288,109). Overall, there were net incoming resources for the year of £18,940 (2023: outgoing £89,184).

Financial Reserves Policy
The Charities SORP requires a charity to state the amount and type of financial reserves it holds, and to compare how the level of those reserves matches up to "The level of reserves the trustees feel as appropriate given their plans for the future activities of the charity". Where it falls short, the trustees need to explain what steps they are taking to rectify the situation. In this context, the charity views financial reserves as those held in its unrestricted funds, the balance of funds stood at £71,832 at the year-end (2023 £52,592).

The Trustees establish the appropriate level of unrestricted reserves (over and above those already ring-fenced for plans or known liabilities within restricted and designated Funds) by seeking to ensure that the level of the charity's 'free reserves' meets a chosen benchmark related to the budgeted expenditure for unrestricted activities. The Trustees consider the "free reserves" to be the unrestricted funds not committed or invested in tangible assets. As a result of a full and objective review of its 'free reserves' policy, considering all the risks foreseeable at that point and the charity's approach to their mitigation, the Trustees agreed on 9th February 2023 that £30,000 should be maintained as 'free reserves'. This level has continued to be reviewed for adequacy and robustness to ensure the Charity maintains adequate finances to meet day-to-day operating costs, and we will continue to review this over the coming months. As of 30 June 2024, the Charity's "free reserves" stood at £71,832 (2023: £52,892), resulting in a surplus of £41,832 (2023: surplus of £22,892) when compared with the current benchmark, calculated as £30,000.

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2024

Strategic approach and plans to fulfil our charitable objectives
In the coming year we plan to:

Objective 1: To identify, fund and monitor medical research projects, clinical trials, clinical trial capacity opportunities and new technological advances.

To receive updates on outcomes for projects funded so we can report on the impact those projects have made to help progress our mission. To report on these via our news feeds on our website, our social media platforms, e-newsletters to our supporters, through local press coverage and at our events.

Continue to work closely with Duchenne UK as a Charity Partner. To seek out and fund new projects that fit with our mission to conquer Duchenne - to improve and extend the lives of everyone affected. Ensuring that our funds are spent effectively and in the right areas to help bring about the best chances of bringing new treatments to market.

Increase our level of income generated each year by building relationships with our existing supporters as well as attracting new supporters to our cause.

Continue to fund projects that will bring about effective treatments, new technologies, improve care standards, and improve clinical trial capacity in the UK for the Duchenne community and aim to give £150,000+ per annum.

Objective 2: To engage with media and our supporters to raise awareness of Duchenne Muscular Dystrophy.

Attend the annual Horizons Conferences held by Duchenne UK to engage with other parents affected by Duchenne Muscular Dystrophy, as well as keep abreast of latest progress made in the field of Duchenne. To be actively involved in workshops and meetings alongside Duchenne UK that is focussed on improving care standards in the UK.

Where possible, attend national events and meetings to help lobby MPs and Parliament to bring about new treatments to market as quickly as possible e.g. Vamorolone and Givinostat.

Issue press releases and submit to the local press in the East Midlands to help raise awareness about the work we are doing and its impact on the local community / the rest of the UK and to help attract new supporters to our cause.

Continue to send monthly updates to our supporters via e-newsletters, add newsworthy content to our website and regularly post and grow our supporter base across our social media platforms.

Organise Supporter events including our annual Spring Launch and our Autumn Lunch to keep in touch with our supporters and guests about the vital work that we do, and how they can continue to help us.

Continue to attend networking events within the region to build new and foster existing relationships and attract new supporters to our cause and arrange 121's with business supporters on how we can collaborate and foster relationships.

Continue to speak at community and business events where opportunities to arise.

Objective 3: Income Generation through our flagship events, supporter events and fundraising activities.

Organise and build on our flagship events: Annual Charity Golf Day, our Supercars event, Charity Football Tournament, Charity Grand Prix event, Fashion Show collaborating with other local charities, our Annual Fundraising Ball and The Big Christmas Give campaign. Our focus is on covering costs, making an impact with the amount of funds raised, and providing a fun and enjoyable fundraising experience for our supporters.

Support other organisations, groups and individuals who have decided to organise their own events in support of our cause, providing resources and time to support them achieve their fundraising goals.

To attract supporters to take part in the London Marathon, walking and running events, challenge events e.g., zipwire challenges, skydiving, loop the loop aerobic displays, wing walks, and abseil challenges and to raise as much money as they can doing so, by providing them with the tools and encouragement to do so.

Retain our existing regular giving supporters and develop new initiatives to grow our regular giving supporter base, through our 'Be More Alex' £7 a month regular giving campaign, our Business Community £75 a month regular subscription in exchange for business benefits such as organising local networking events to bring the local business community together.

Continue to support businesses who donate a percentage of their income to us every single month and look to attract like-minded business.

We aim to work within a 30:70 ratio of cost vs. income received from an event to ensure that 70% of what we raise from our events overall goes directly to fund projects to further our mission. We would like to attract more capital through corporate sponsors to cover most/if not all our event costs to help improve this ratio further. We have been successful in attracting corporate sponsors and will continue to build on those relationships.

Majority of our income raised has been through hosting our own events. Our aim is to continue working with local businesses to take Alex's Wish on as their chosen charity and organise their own events and consider Alex's Wish as their Charity of the Year. This means that 90%+ of the money they give to us as a Charity goes directly to fund projects to further our mission as they do not incur the expenditure that our own fundraising activities require.

Continue to work with charitable foundations who have kindly supported our work, as well as other local charitable groups, to source additional income. We are now outsourcing this important work to an expert in this field to help us identify and approach new trusts and foundation opportunities. We have seen success in this field, and hope to continue to find more success as we diversify our income streams.

Form strategic alliances and partnerships with organisations such as local sporting clubs, colleges, schools, and corporate businesses.

We hope in the future to launch a podcast to further our reach and attract new audiences to our cause.

Structure, governance and management
Governing document
The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Trustee Recruitment
Trustees will be recruited through recommendations and social media, at our events and through word of mouth. Those expressing an interest will, in the first instance, be met by the Charity Founder, given an overview of the organisation, and encouraged to apply. The Chair and Co-Chair trustees will examine the applications against the most recent skills audit, produce a short list, and invite those on it to submit their references and then attend an interview; the Chair and Co-Chair will conduct the interviews, and make recommendations to the Board. At its next meeting, the Board will review these recommendations, and either ratify or reject. Successful applicants will be asked to complete and sign the declaration of interest form, sign a declaration that they are eligible to serve as a trustee; and agree to the code of conduct. They will then become a trustee of the Board.

Organisational structure
The organisation is a charitable company limited by guarantee, incorporated on 22 June 2012. The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £10.

The body responsible for management of the Charity is the Board of Trustees of Alex's Wish. The Board meets monthly (and at least ten times per year). The charity's constitution is set out in the Articles of Association, and all Trustees have agreed to this. New Trustees are appointed by the existing Board of Trustees. Trustees give of their time freely and no Trustee remuneration was paid in this year. Details of Trustee expenses and related party transactions are disclosed in the accounts. Trustees are required to disclose all relevant interests and to withdraw from decisions where a conflict of interest arises. None of the Trustees have any interests with the pharmaceutical industry.

We regularly review our stated aims, objectives, and activities to ensure we are working toward our stated purposes. We have referred to the guidance contained in the Charity Commission's general guidance on public benefit under the Charities Act 2011 when setting and reviewing our aims and objectives and in planning our future activities. All our charitable activities focus on improving the lives of those with Duchenne Muscular Dystrophy.

Risk management
The Trustees continue to review the major strategic, business, and operational risks which the charity faces and confirm that systems are in place to enable regular reports to be produced so that the necessary steps can be taken to lessen these risks. In assessing risk, the Trustees recognise that some areas of the work require the acceptance and management of risk if the charity is to achieve its objectives.

Approved by order of the board of trustees on 25 March 2025 and signed on its behalf by:



Mrs E J Hallam - Trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF ALEX'S WISH

Independent examiner's report to the trustees of Alex'S Wish ('the Company')
I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2024.

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

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

Independent examiner's statement
Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Association of Chartered Certified Accountants, which is one of the listed bodies.

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

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

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



J Petha FCCA
The Association of Chartered Certified Accountants

Sturgess Hutchinson
Chartered Certified Accountants
21 New Walk
Leicester
LE1 6TE

25 March 2025

ALEX'S WISH

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2024

	Notes	2024 Unrestricted fund £	2023 Total funds £
Income and endowments from			
Donations and legacies		37,644	43,447
Charitable activities			
Fund-raising activities		248,269	300,297
Investment income	2	1,168	834
Total		287,081	344,578
Expenditure on			
Charitable activities			
Expenditure on charitable events		46,471	51,201
Administrative services		79,555	66,419
Payments for medical research, clinical posts and new technologies		113,000	288,109
Support costs		29,115	28,033
Total		268,141	433,762
NET INCOME/(EXPENDITURE)		18,940	(89,184)
Reconciliation of funds			
Total funds brought forward		52,892	142,076
Total funds carried forward		71,832	52,892

The notes form part of these financial statements

ALEX'S WISH

BALANCE SHEET
30 JUNE 2024

	Notes	2024 Unrestricted fund £	2023 Total funds £
Current assets			
Debtors	7	16,083	12,979
Cash at bank and in hand		68,138	54,949
		84,221	67,928
Creditors			
Amounts falling due within one year	8	(12,389)	(15,036)
Net current assets		71,832	52,892
Total assets less current liabilities		71,832	52,892
NET ASSETS		71,832	52,892
Funds	9		
Unrestricted funds		71,832	52,892
Total funds		71,832	52,892

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 June 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 30 June 2024 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for
(a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
(b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 25 March 2025 and were signed on its behalf by:

Mrs E J Hallam - Trustee

The notes form part of these financial statements

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2024

1. Accounting policies

Basis of preparing the financial statements
The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) '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)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Income
All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure
Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Taxation
The charity is exempt from corporation tax on its charitable activities.

Fund accounting
Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Hire purchase and leasing commitments
Rentals paid under operating leases are charged to the Statement of Financial Activities on a straight line basis over the period of the lease.

Pension costs and other post-retirement benefits
The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. Investment income

	2024	2023
	£	£
Deposit account interest	1,168	834

3. Net income/(expenditure)

Net income/(expenditure) is stated after charging/(crediting):

	2024	2023
	£	£
Other operating leases	7,140	3,570

4. Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year ended 30 June 2024 nor for the year ended 30 June 2023.

Trustees' expenses

There were no trustees' expenses paid for the year ended 30 June 2024 nor for the year ended 30 June 2023.

5. Staff costs

	2024	2023
	£	£
Wages and salaries	77,943	64,946
Other pension costs	1,612	1,473
	79,555	66,419

The average monthly number of employees during the year was as follows:

	2024	2023
Administration	3	3

No employees received emoluments in excess of £60,000.

6. Comparatives for the statement of financial activities

	Unrestricted fund
	£
Income and endowments from	
Donations and legacies	43,447
Charitable activities	
Fund-raising activities	300,297
Investment income	834
Total	344,578
Expenditure on	
Charitable activities	
Expenditure on charitable events	51,201
Administrative services	66,419
Payments for medical research, clinical posts and new technologies	288,109
Support costs	28,033
Total	433,762
NET INCOME/(EXPENDITURE)	(89,184)
Reconciliation of funds	
Total funds brought forward	142,076
Total funds carried forward	52,892

7. Debtors: amounts falling due within one year

	2024	2023
	£	£
Trade debtors	2,165	3,290
Prepayments and accrued income	13,918	9,689
	16,083	12,979

8. Creditors: amounts falling due within one year

	2024	2023
	£	£
Social security and other taxes	409	655
Accruals and deferred income	11,980	14,381
	12,389	15,036

9. Movement in funds

	At 1.7.23	Net movement in funds	At 30.6.24
	£	£	£
Unrestricted funds			
Unrestricted funds	52,892	18,940	71,832
TOTAL FUNDS	52,892	18,940	71,832

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Unrestricted funds	287,081	(268,141)	18,940
TOTAL FUNDS	287,081	(268,141)	18,940

Comparatives for movement in funds

	At 1.7.22	Net movement in funds	At 30.6.23
	£	£	£
Unrestricted funds			
Unrestricted funds	142,076	(89,184)	52,892
TOTAL FUNDS	142,076	(89,184)	52,892

Comparative net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Unrestricted funds	344,578	(433,762)	(89,184)
TOTAL FUNDS	344,578	(433,762)	(89,184)

10. Related party disclosures

There were no related party transactions for the year ended 30 June 2024.

ALEX'S WISH

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2024

	2024 £	2023 £
Income and endowments		
Donations and legacies		
Donations	37,644	43,447
Investment income		
Deposit account interest	1,168	834
Charitable activities		
Fund-raising activities	248,269	300,297
Total incoming resources	287,081	344,578
Expenditure		
Charitable activities		
Annual Golf Day	4,794	4,538
Prudential Ride London	-	945
Annual Fundraising Ball including cost of auction prizes	26,199	20,807
Our Business Community	355	429
London Marathon	2,592	3,531
Supercars Charity Event	4,778	6,696
'Be More Alex' regular giving campaign	481	783
Abseil Charity Event	1,272	1,145
AGM / Annual Supporters Thank You Lunch	3,774	5,009
Miss Great Britain Finals Event	1,025	639
Skydiving Events	-	2,768
Football Event	1,088	448
Loop the Loop Challenge with AeroSparx	1,153	2,218
Stan Hulme's Nordic Challenge	-	109
Other sundry event costs	-	150
Big Give Christmas Challenge	60	60
Fashion Show	-	100
Spring Launch	1,247	826
Grand Prix Event	110	-
Kazoo Pink Ball	914	-
	49,842	51,201
Support costs		
Management		
Wages	77,943	64,946
Pensions	1,612	1,473
Office Rent	7,140	3,570
Insurance	864	730
Business Development & Networking Events	2,063	5,763
Postage and stationery	1,349	213
Promotional materials	2,793	4,907
Office equipment	713	2,092
Bookkeeping and legal fees	257	278
Travel and subsistence	1,846	1,824
Bank charges	370	358
Staff Training and Welfare	995	366
Computer and software costs	3,690	5,142
Website and email marketing	874	450
Accountancy	2,340	2,340
Carried forward	104,849	94,452

ALEX'S WISH

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2024

	2024 £	2023 £
Management		
Brought forward	104,849	94,452
Business services	450	-
	105,299	94,452
Other		
Payments for Medical Research, Clinical Posts and New Technologies	113,000	288,109
Total resources expended	268,141	433,762
Net income/(expenditure)	18,940	(89,184)

ALEX'S WISH

England & Wales - Charity number 1148845

Accounts

REGISTERED COMPANY NUMBER: 08116159 (England and Wales)
REGISTERED CHARITY NUMBER: 1148845

TRUSTEES' REPORT AND

UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2023

FOR

ALEX's WISH
cure Duchenne

ALEX'S WISH
(A COMPANY LIMITED BY GUARANTEE)

Sturgess Hutchinson
Chartered Certified Accountants
21 New Walk
Leicester
LE1 6TE

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FOR THE YEAR ENDED 30 JUNE 2023

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ALEX'S WISH

REFERENCE AND ADMINISTRATIVE DETAILS
FOR THE YEAR ENDED 30 JUNE 2023

Trustees	Ms S L Barnett Mr T W Carter (resigned 1/10/2023) Ms J Edwards Mr C R Everard Mrs E J Hallam Mr A R Hallam Ms A L Slack Ms K Boorman (resigned 1/10/2022) Mr S Jesrani Ms G Wright
Registered office	The Old Vicarage High Street Syston Leicestershire LE7 1GP
Registered company number	08116159 (England and Wales)
Registered charity number	1148845
Independent examiner	Sturgess Hutchinson Chartered Certified Accountants 21 New Walk Leicester LE1 6TE
Website	www.alexswish.org
Bankers	National Westminster Bank 5 The Parade Oadby Leicester LE2 5NT

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2023

The Trustees, who are also Directors of the charitable company for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 30 June 2023. The trustees have adopted the provisions of 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).

Scientific Advisory Board
We work closely with Duchenne UK as their Charity Partner and as such, most projects that we fund are co-funded alongside them. All projects put forward to us for potential funding go through their rigorous Scientific Advisory Board, which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy. It includes the different skills of doctors, scientists, and drug developers so that each project is asked the right questions: Is this good science? Can this be taken into clinic? What hurdles exist? Is this replicated anywhere else?

Duchenne UK's advisory board consists of:

Professor Dame Kay Davies
Dr. John Bourke
Dr. Dada Pisconti
Dr. Valeria Ricotti
Professor Giovanni Baranello
Professor Jordi Diaz Manera
Dr. Tina Duong
Dr. Isabelle Richard
Dr. Carina Schey
Professor Francesco Saverio Tedesco
Dr. Graeme Wilkinson

Alex's Wish would like to thank its Trustees, employees, service providers and supporters for kindly giving their time and expertise to grow the charity.

Statement from the CEO and Charity Founder, Emma Hallam

Alex's Wish was launched in late 2012 after our son, Alex, was diagnosed with Duchenne Muscular Dystrophy. When the diagnosis was confirmed, we were absolutely devastated as doctors told us there was **NO CURE** and **NO TREATMENTS** available other than steroids which cause serious side-effects and, at best, would help delay the onset of his condition by two years at most.

Duchenne is a life-changer. It affects every single day of your life as you must be prepared for ever-changing challenges that affect your child's/young adult's day to day activities. Duchenne is a progressive, muscle wasting disease. It is relentless, affecting every single muscle in the body. One day your child may not be able to walk, may not be able to lift a cup to their mouth, may not be able to access their friends' houses anymore. We felt overwhelmed and terrified of what the future held for our son, living in fear of the next stage of progression and wondered how we would cope.

At the time of diagnosis, we quickly realised we had no time to waste, and that funding was the main cause of concern. So, we set-up Alex's Wish, a charity based in the heart of Leicestershire, as we knew we would attract interest and support from the community across the East Midlands and beyond, bringing in additional funds to what was already being raised. We do not duplicate efforts of other charities working in this field, instead our focus is to **drive additional funds**, allowing us to co-fund projects with other charities like Duchenne UK.

The science is at a very exciting time; a time of optimism as new treatments are now starting to emerge. We were told that Gene Therapy wouldn't happen in our son's lifetime. However, we are now seeing patients taking part in Gene Therapy Clinical Trials in the UK.

The research we have funded is now bearing fruit. Vamorolone a steroid-alternative drug, that has less harmful side-effects to traditional steroids has now been approved by the Medicines and Healthcare products Regulatory Agency (MHRA) for use in children aged four upwards living with Duchenne in the UK and is currently with NICE for approval. We are incredibly proud that we were able to invest in the early stages to make this a reality.

We've seen the development of new prototype technologies; The Smart Suit and The DREAM Wheelchair starting to emerge and showing great promise, and Alex's Wish has been supporting these projects.

A clinical trial which our own son Alex has been on for the past 5 years, called **Givinostat run by Italfarmaco**, announced in the Summer of 2022 that the drug is working to help slow down disease progression. This is great news for the Duchenne community as a whole and brings with it so much hope for the future. For more details, visit Givinostat Positive Top-line Results Release.

With all this progress, we cannot help but feel incredibly optimistic that more effective treatments will emerge, and new innovative technologies will become available alongside improved care standards to help everyone living with Duchenne. The hard work is paying off, but we must continue our journey and fund the projects we've already invested in to get those to the next stages, as well as find new discoveries to slow down and ultimately stop muscle wasting. Our mission is not only to eradicate Duchenne, but to slow down the disease and help those living with the Duchenne live the best lives possible with new technologies and improved standards of care.

We are delighted with our progress to date and excited about the times ahead. We are incredibly grateful to our wonderful supporters who have come on this journey with us so far. We would like to say a **very special thank you** to the following people and organisations.

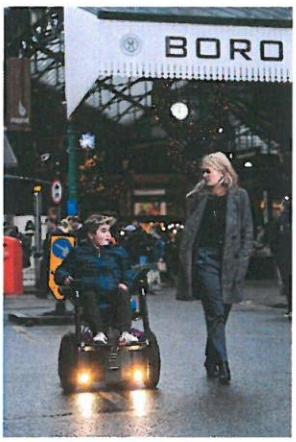
- Duchenne UK, a charity run by two mums (Emily Crossley OBE and Alex Johnson OBE) who have sons Eli and Jack who also live with Duchenne, for their incredible work and by collaborating with them, we ensure we only ever invest in the best science and technologies available.
- Our fundraising team Zoe Edwards, Heidi Eastell (who left Alex's Wish in July 2023), Bev Bailey who replaced Heidi in October 2023 and Heather Stone for their enthusiasm, hard work, and support. They contribute significantly to the day-to-day running of the Charity and its success.
- Our dedicated Trustees for their continued support, help in running the charity, providing a great platform to discuss future goals and initiatives, much-valued feedback and for their introductions to new supporters.
- To our major donors and Charitable Foundations for their financial contributions during this period, including (but not limited too) The Brothers Trust, With Love, Steph Foundation, St. James's Place Charitable Foundation, Netmetix, Miss Great Britain, Spirit Healthcare, Janine Edwards Wealth Management and Strategic Insurance Services.
- To those businesses who offer pro-bono work: Sturgess Hutchinson for our annual accounts, Flexpress for print and production, New English Design for website hosting, Winstanley House for hosting our Business Club events at their venues, Delta Global for our promotional bags, Fashion UK for our branded t-shirts, Steven Havers Business Photography for our event photography, David Sinclair (Corporate Motion) for event videography, FU Media for the development of our media press releases, and Brooksure Insurance for our annual insurance to keep our running costs low, and to those suppliers who work with us providing services at reduced costs.
- Every business, club and supporter who has either chosen us as their Charity of the Year, sponsored our events, organised events for us, attended our flagship events and taken part in various challenges, donated items and experiences for our fundraising auctions and raffles, our business club members and to our ambassadors who shout from the rooftops about the work we do. There are too many to list individually, however we thank all businesses who support our cause at our annual Autumn Lunch, and feature supporter stories across our social media sites and through our news stories which are also released to the local media.

In this financial year, we have invested £288,109 in five projects (2021/22 £117,000 in four projects):

- **Gene Therapy Grant Call - £80,000.00, of which £20,000 was kindly received from The Brothers Trust and £3,000 was received from With Love, Steph Foundation** - Over the last few years, we have seen huge progress in the development of potentially transformative treatments, such as gene therapies, with a few currently being tested in patients. However, the impact of these therapies is hindered by significant limitations, associated with their safety and efficacy profile. This project which we have collaborated on with Duchenne UK, aims to address these limitations by taking advantage of innovative technologies that have led to the development of novel muscle regeneration approaches, based on muscle stem-cells and other approaches which harness the patient's muscle cells ability to regenerate. Through the call, two proposals have been identified, from a pool of seven submitted by organizations worldwide, and have been progressed to full project plans.
- **The Smart Suit - purchase of a prototype - £70,000.00, of which £50,000.00 was kindly received from The Brothers Trust**. When a person loses their upper body function basic tasks like brushing their teeth, feeding themselves, or hugging family become impossible. Physical barriers and social barriers (assumptions about their role and value in society) restrict freedom. Eventually, the barriers become insurmountable, removing the ability to live independently, continue in education, secure a job, or sustain a social life. A third of pupils aged 11-15 with a long-term illness, disability or medical condition said their disability negatively impacted their ability to participate in education. Ultimately, they're removed from public life and become invisible, so too do their voice and needs. This must change. The SMART Suit will give back what Duchenne steals from young people, by restoring the use of their arms and, just as Batman's suit transformed a normal man into a superhero, The SMART suit will transform disabled kids into independent teenagers living with dignity. It will transform their lives by ultimately delivering a measurable impact on inclusion, educational attainment, and participation in society at large. We are collaborating with Duchenne UK on this project, which is designed not just to benefit the UK, but worldwide, as well as other disease areas and conditions with loss of upper body function. We are extremely grateful to our wonderful supporters and to The Brothers Trust for their contribution towards this project.




- **DMD Care - Nutritional Project - £50,846.18**. Obesity is a serious health complication in Duchenne, with negative implications on cardiac and respiratory function, mental health, and quality of life. Numerous factors contribute to weight gain, including limited physical activity and the use of long-term steroids. Whilst the need for better diet and nutritional management in boys with Duchenne is recognised, this aspect of care is not addressed in the NHS, due to lack of resources and specific guidance. The solution is to develop the evidence required to affect change in Duchenne weight management care and a range of resources, tailored to the needs of boys with Duchenne and their families, that they can access particularly after initiation of steroid treatment. There is currently no structured nutritional and weight management guidance available to boys with Duchenne in the UK. A UK wide survey of families of boys (via DMD Care UK) showed that for 46% of patients, nutritional issues are not monitored or addressed in the clinic. The survey also highlighted that Duchenne specific nutritional and lifestyle advice is considered essential by these families. The 2018 international standards of care recommend that a registered dietician should assess nutritional status and create a specific nutritional plan, both of which are currently not available to UK patients through the NHS. Taken together, these highlight a major gap in UK care of boys with Duchenne, which we are uniquely placed to help address through DMD Care UK and funding this project.
- **DMD Care - Programme Manager - £22,245.00.** Towards the costs of a Programme Manager salary to continue to deliver DMD Care UK, a flagship programme that is driving better clinical care for all people living with Duchenne in the UK. Despite the huge impact achieved by DMD Care UK since its launch nearly 3 years ago, there is still a lot of work that we need to do to drive improvements of DMD care in the UK, educate the UK community, and to empower patients and families to access the best care, regardless of where they live in the UK. This is why we want to continue to support DMD Care UK, a flagship programme which is about to launch its new programme of work for the next 3 years. This will include continuing work to drive the development, dissemination, and adoption in the NHS of new DMD expert guidance for all areas of clinical management, including psychological support. The programme will also focus on developing tools and resources that families can access freely, support them to be active participants in their own care and achieve better outcomes. DMD Care UK is a complex programme that brings together a large group of patients, clinicians, and other stakeholders and many important workstreams that need to be coordinated and actively managed.
- **The DREAM Wheelchair - £65,000, of which £20,000 was kindly received from St. James's Place Charitable Foundation, £5,000 from The Brothers Trust and £3,000 from With Love, Steph Foundation.** For children and young people like Alex, using a wheelchair makes all the difference to their independence. But, despite huge advances in technology in almost every area of life, design and functionality of wheelchairs has changed little in 15 years. Getting up a kerb, seeing what is behind you, even having somewhere to put your phone – things the rest of us barely notice in our lives – are major tasks for young wheelchair users. The DREAM wheelchair project is designed to bring wheelchairs into the 21st century, transforming young lives. We're extremely grateful to our wonderful supporters, and to The St. James's Place Charitable Foundation, The Brothers Trust and With Love, Steph Foundation for their contributions towards this project.






We are incredibly positive about the future and Alex's Wish gives us hope. Duchenne Muscular Dystrophy is part of our lives, not out of choice, but we will make it as best as we can, and we will never stop our journey to conquering Duchenne. We could not have done our work without our army of supporters, the charitable foundations who have supported us, the local business community, our business sponsors, our fundraising team, ambassadors and our dedicated trustees and we would like to express our gratitude and thanks to every single one of them.

Emma Hallam
Charity Founder and CEO

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2023

About Duchenne Muscular Dystrophy

Duchenne Muscular Dystrophy is a devastating life-limiting genetic disease that affects 1 in every 3,500 boys born (it also affects girls who account for 1% of all those diagnosed). It is caused by a mutation in the gene that encodes for dystrophin, a protein that is essential to the proper functioning of our muscles. Without dystrophin, muscles are not able to function or repair themselves properly. The loss of muscle then results in a loss of strength and function.

Duchenne can be passed from parent to child, or it can be the result of random spontaneous genetic mutations, which may occur during any pregnancy. In fact, about one out of every three cases occurs in families with no previous history of Duchenne. In other words, it can affect anyone, and crosses all races and cultures. The average age of a Duchenne diagnosis is around 4 years old. Many times, there will be delays in early developmental milestones such as sitting, walking, and/or talking. Speech delay and/or the inability to keep up with peers will often be the first signs of the disorder.

Duchenne progresses differently for every person. Even siblings with the same mutation may have a very different progression of symptoms. Muscle loss is first noticed in childhood, with loss of strength, function, and flexibility in the hips, thighs, shoulders, and pelvis. In teens these losses begin progressing to the arms, lower legs, and trunk. Because there is also an absence of dystrophin in the muscles of the heart and lungs, heart function and breathing are also affected. In addition, some people can have issues with learning and behaviour resulting from a lack of dystrophin in the brain.

The progression of symptoms through Duchenne are on a spectrum from late onset/very mild symptoms to early onset/severe symptoms. Regular visits with a neuromuscular team help to monitor the progression of disease and how it can best be treated along the way. With improved care more people with Duchenne are living into their 20s and 30s. With clinical care continuing to improve, as well as clinical trials, research, and therapies on the horizon, we are hoping to enhance the quality of life and extend the lives of those affected.

Duchenne in numbers

- 1 of the most serious genetic diseases in children.
- 1 in every 3,500 boys born will have Duchenne.
- 2,500 boys affected in the UK.
- 300,000 boys affected worldwide.
- 2 families per week receive diagnosis in the UK.
- 90% of boys will require the use of a wheelchair by the age of 12.

What we are doing about it

We are committed to continuing to drive momentum to deliver treatments to help **THIS generation** of those with Duchenne. We have invested £1,067,574 into 36 different projects ranging early-stage scientific research, clinical trials, funded clinical posts ensuring patients living in the UK can access trials, funded projects to improve care standards in the UK, as well as new technological advances. We have an innovative approach to funding. Not only do we fund basic research, but we fund clinical trials and the doctors and nurses in the UK to deliver those trials.

Our Vision

Our Vision is a world without Duchenne Muscular Dystrophy. We want a future that stops the devastating impact Duchenne has on our children and young adults, a future where they can grow and prosper and fulfil their dreams. A life where they can enjoy every day without the fear of the progression this muscle wasting disease has on their bodies. A future without Duchenne would be a bright and happy future for all those affected. We need to act quickly to save this generation. Doing nothing is not an option. Our boys and their families need to live without fear and have hope for the future.

Our Mission

We have one clear mission; to conquer Duchenne for this generation. Our ultimate focus is to **extend** the lives of those living with Duchenne right now, to halt and ultimately reverse the effects of muscle wasting. Whilst also supporting the delivery of excellent standards of care and new technologies to help **improve** the lives of those affected.

Alex's Wish was set-up by a family affected by Duchenne, who understand first-hand the impact this condition has on their child and the family. As a family we are taking part in clinical trials ourselves as we understand the importance of clinical trials and how they will help bring effective treatments to market. Charities like ours fund half of all medical research in the UK to the tune of £1.7bn. Today, 1 in 4 people choose to support medical research charities like ours, and for this we are so incredibly grateful.

Our Progress

Continue to increase funds raised each year despite the impact of the Pandemic in 2020 and 2021.

- Y1 - 1 July 2012 to 30 June 2013 - £53,025
- Y2 - 1 July 2013 to 30 June 2014 - £83,962
- Y3 - 1 July 2014 to 30 June 2015 - £134,263
- Y4 - 1 July 2015 to 30 June 2016 - £124,885
- Y5 - 1 July 2016 to 30 June 2017 - £157,626
- Y6 - 1 July 2017 to 30 June 2018 - £197,688
- Y7 - 1 July 2018 to 30 June 2019 - £218,518
- Y8 - 1 July 2019 to 30 June 2020 - £201,178

- Y9 - 1 July 2020 to 30 June 2021 - £129,778 (reduction in funds raised due to the COVID Pandemic)
- Y10 - 1 July 2021 to 30 June 2022 - £225,880
- Y11 - 1 July 2022 to 30 June 2023 - £341,360

We continue to increase funding into innovative projects year on year and invested a total of £1,067,574.

- Y2: £28,415
- Y3: £74,100
- Y4: £73,661
- Y5: £92,862
- Y6: £112,143
- Y7: £144,142
- Y8: £75,000
- Y9: £62,142
- Y10: £117,000
- Y11: £288,109

Objectives and Activities

1. The principal objects of the charitable company are the relief of sickness and the preservation of good health by supporting scientific research into the improved diagnosis, prevention, or treatment of Duchenne Muscular Dystrophy by:
   a) Extending the current scope of drugs / treatments so that they will help all children with Duchenne Muscular Dystrophy.
   b) Fund first stage clinical trials that provide the safety and efficacy of some of these treatments and then progress this into larger scale production.
   c) Fund the completion of scientific work already begun, to bring it to clinical trials, and fund other forms of treatment that will work on all children regardless of their genetic mutation.
   d) Fund studies that will bring about data and information to help decision makers make decisions on which treatments to bring to market.
   e) Fund the DMD Care programme empowering patients/families to access the best care wherever they live in the UK.
   f) Fund new technological advances to help children and young adults living with Duchenne live a better quality of life.
2. Advance the education of the public, in all areas relating to Duchenne Muscular Dystrophy by disseminating information on the disease and its treatments and cures. To:
   a) Disseminate information using online and offline materials, including the Alex's Wish Website and via our monthly e-newsletters to our supporters.
   b) Running events and fundraising activities, including our Spring Launch and Autumn Lunch which sees our team, trustees, representatives from Duchenne UK, and our supporters come together for us to share our impact during the last 12 months and our plans.
   c) Promoting our work across a variety of social media platforms:
      Facebook FACEBOOK PAGE
      You Tube YOU TUBE PAGE
      LinkedIn LINKED IN PAGE
      Instagram INSTAGRAM PAGE
   d) We have built great relationships with the local media outlets in our region including ITV Central and BBC East Midlands and regularly generate news articles and updates in local newspapers, including The Leicester Mercury, The Loughborough Echo and local magazines posted through doors. We appear regularly on the local radio stations including BBC Radio Leicester to raise awareness about Duchenne and the impact this has on families living with it.
   e) Talking and presenting at various events on Corporate Social Responsibility, the impact of living with Duchenne Muscular Dystrophy, About Alex's Wish and Resilience - it is important our personal story is shared amongst others to be the voice for other families affected by Duchenne.
   f) Participate in alliances and liaise with the Government to inform policy makers and other stakeholders about the work of the charity, the nature of the disease and potential treatments and cures.

Our Grant Making Policy and Collaboration

The Charity has established its grant making policy to achieve its objectives for the public benefit to find a cure for Duchenne Muscular Dystrophy and to slow down the rate of progression by maintaining muscle strength for longer leading to increase life expectancy as well as a better quality of life.

We only want to fund great science - projects that can improve the knowledge base and bring treatments that can reach the clinic and improve the lives of boys with Duchenne Muscular Dystrophy in many ways. We want to fund new technologies that will go on to help those affected by Duchenne, by making the world accessible to them.

We formed a partnership with Duchenne UK. Duchenne UK share the same mission and objectives as Alex's Wish and are also a parent-led charity. As a Charity Partner to Duchenne UK, we receive projects that require co-funding. All such projects have been reviewed extensively by their Scientific Advisory Board which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy. They bring with them a wide range of essential skills and knowledge basis including scientific,

clinical and drug discovery and development. When scientists approach Duchenne UK with their ideas for new research projects it is the SAB who apply their experience and expertise to test these ideas, helping to refine them, if necessary, in order that Duchenne UK can make informed decisions on funding. Alex's Wish Trustees review all projects put forward before deciding upon specific projects to fund.

We also work with Solid Biosciences to help progress their Gene Therapy programme and this work is now progressing into clinical trials and is showing great promise.

We have worked previously with Muscular Dystrophy UK to co-fund research and clinical trials. Alex's Wish is part of the Duchenne Forum, a partnership between six UK Duchenne-led charities to help accelerate progress in the search for effective treatments and eventually cures. The partnership has supported seven pioneering Duchenne research projects committing to £840,000 over a four-year period.

We have worked with Action Duchenne and co-fund projects as such as the Repurposing Cancer Therapeutic drug called Dasatinib - a drug commonly used to treat leukaemia.

We regularly send updates on project performance and outcomes to our supporters through a monthly e-newsletter as well as publish updates on our social media channels, news articles on our website and submit press releases to the local media companies. We have appeared on BBC East Midlands Today and ITV Central.

Achievement and Performance
Co-funded 36 projects across a broad-spectrum from early-stage research through to clinical trials, funded 5 clinical posts to support clinical trial development and patient access, funding DMD Care projects, as well as invested in new technologies. Here are just a few examples of the work we have funded.

Gene editing therapy to accelerate the investigations needed to translate stem cell-based approaches or gene therapies into clinical trials or application in patients. The funding for this project will support testing a gene-editing therapy for Duchenne in preclinical models. This study is making great progress against all aims. Small and large animal studies are now underway.

DMD Hub Manager is a flagship project that has successfully expanded capacity for clinical trials for Duchenne treatments in the UK. In the first four years of the project, Duchenne UK, and its partner charities (including Alex's Wish) invested £2.7m in the DMD Hub, with an additional £1.6m committed over the next 4 years. The DMD Hub is a collaboration between Duchenne UK, the John Walton Muscular Dystrophy Research Centre (JWMDRC) in Newcastle, and Great Ormond Street Hospital London. It was set up to expand clinical trial capacity and expertise and stop clinical trials being turned away from the UK. The project team developed the Clinical Trial Finder to help patients access information on DMD clinical trials in the UK. Thanks to the DMD Hub, to date, more than 574 boys have been recruited since it was established in 2016 to clinical trials who otherwise may not have been. Emma Heslop is the DMD Hub Manager and is key to the success of this project. Working closely with the Duchenne UK team, she ensures patients are appropriately represented as key stakeholders in all aspects of the DMD Hub. As part of the team at the JWMDRC in Newcastle, she has direct access to clinicians and industry partners through the relationships she has cultivated over the years. As the main point of contact for all companies with trials coming to the UK, she also promotes the UK as an attractive place to run DMD trials and works with them to support site selection, set up and patient recruitment.

Antifibrotic screening platform (a new molecular biology technique which enables us to look inside muscle cells for Duchenne patients. This will help us to understand which treatments are most effective in preventing fibrosis, a process which happens when muscle cells die and are replaced by fatty tissue. Fibrosis can lead to failure of the heart and respiratory muscles, which is the most common cause of death in adults with Duchenne. While gene therapies could be transformative for people living with Duchenne, the progressive nature of the disease limits their impact. Combining gene therapies with drugs that could reduce muscle deterioration, such as anti-fibrotics could help to maximise the effect of these treatments. Anti-fibrotics could also be used to treat patients who are not eligible for gene therapy, and for those in the later stages of the disease. We funded a PhD post who was successfully appointed in August 2022 and substantial progress has been made during the first year, the interim report showed that the first aim of characterising the potential cytotoxic effect of the selected drugs in vitro has been completed and treatment proved safe to progress to in vivo studies in mouse models.

Lipid Nanoparticles (LNPs) technology used in COVID-19 vaccine to see whether it could be used to help in gene therapy treatments for Duchenne. Lipids are naturally occurring small fatty molecules that exist within the body, and nanoparticles refers to their small size. LNPs are currently being used as a key component in the Pfizer/BioNTech and Moderna COVID-19 vaccine. Several clinical trials of gene therapy are now underway in Duchenne using harmless viruses, called AAVs, to deliver synthetic gene to replace the faulty dystrophin gene in Duchenne. The early data looks promising. But there are some challenges in getting this treatment to the entire Duchenne population, mainly because some patients will have pre-existing antibodies to the virus and so will not currently be able to have the treatment. There are also difficulties in transferring the genes from the viruses into muscle cells. This study aims to address some of these challenges by exploring LNPs as a method of delivering gene therapy. The study is called 'mRNA Targeted Therapeutics for Duchenne Muscular Dystrophy' and will be led by Professor Shenhav Cohen at Technion Institute of Technology, Israel, in partnership with Professor Aartsma-Rus at Leiden University Medical Center and Professor Peer at Tel Aviv University. LNPs can be filled with a variety of materials, including genetic material. Because LNPs are made of naturally occurring lipids, they should not cause an immune response. They also

have a good safety profile for use in humans. This study will explore whether a larger dystrophin construct can be carried by the LNPs. The dystrophin gene is the largest gene in the body, but in current gene therapy trials, a shortened construct must be used. Our current understanding of the impact of shortened dystrophin on long-term muscle function is limited, but using a longer gene could lead to better muscle function. The research group plans to engineer the LNP surface such that the LNP will effectively fuse with muscle and deliver its cargo. This research is currently in very early stages. If the researchers can show that this method can effectively deliver genetic material into muscles using a mouse model of DMD, they would have a high chance of receiving a much larger grant for further research. The 1-year report was received in May 2022, and highlighted the need for an extension, which was granted. The project team successfully completed the preparation of the nanoparticles; however they were delayed in starting the animal studies, which is now underway.

We Invested in a pioneering Pluripotent Stem Cell Therapy 'Altering the muscle environment to influence stem cell behaviour' at The University of Minnesota which is looking at regenerating muscle in Duchenne patients with stem cells. Stem cells are a potentially exciting approach to generate new healthy muscle in patients with Duchenne. The stem cells we are looking at are called human induced pluripotent stem cells (iPSCs). These cells replace the diseased muscle tissue with stem cells that can create healthy myofibers which are able to regenerate. The aim of this project is to produce and test these stem cells to get the preclinical data required to progress to a clinical trial. This project has proved highly successful, and the success of the findings has led to IND-submission and the initiation of a Phase 1 Clinical Trial in 2024.

A study that is paving the way for improved detection of heart disease in female carriers of Duchenne with De Lee Borthwick and Dr John Bourke at Newcastle University - following this investment, we are pleased to say that this project has improved understanding of heart muscle disease in female carriers, paving the way for further research. Women and girls who carry a mutated Duchenne gene (carriers) can sometimes show mild symptoms of the diseases. Duchenne carriers are at risk of developing cardiomyopathy, which affects the ability of the heart to pump blood around the body. Currently Duchenne female carriers are advised to have their hearts checked every 3-5 years by taking scans such as ECG, echocardiogram, or MRI. However, quicker, and more cost-effective ways to detect heart problems would prevent late diagnosis and enable earlier treatment. De Borthwick and Bourke examined the heart tissue of patients and used this to identify molecules in the blood that could act as biomarkers (indicators of damage to the heart). This study has now ended, and the preliminary data shows these biomarkers have the potential to detect early cardiomyopathy in a way that is fast, reliable and cost-effective. The biomarkers need to be tested in cohorts of female carriers, as well as male Duchenne patients, to be fully validated. This pilot project has laid vital foundations for future research to improve the speed of diagnosis and treatment of cardiomyopathies.

We helped fund a PhD post at The John Walton Muscular Dystrophy Research Centre at Newcastle University specifically to look at the FOR-DMD Study (finding the optimum Steroid regime for boys living with Duchenne) supervised by Dr Michela Guglieri. The PhD post will ensure that the data generated by the FOR-DMD study will be used to address new clinical and research questions, and well as sharing the results with the community, possibly through a series of webinars in 2024.

We are helping improve the success rate of clinical trials (PC Slices) this project is working with Professor Mann and Dr Borthwick from the Newcastle Fibrosis Research Group in the University Biosciences Institute. We had some devastating news at the end of 2019: the early termination of a clinical trial run by Wave Life Sciences. The news was a big blow, not least because early data in animals had shown that the drug was effectively producing dystrophin. How could a trial that showed such a promise in animal models not deliver results in humans? Early-stage tests are done on mice with Duchenne and then transferred to trials in people - but there is uncertainty whether a drug might behave the same in the human body. We want to stop this. That's why we supported this project, which has the potential to help us understand, at a much earlier stage of research, whether a medicine will help treat Duchenne patients. The project has been hit by a reduction in elective surgeries and heart transplants due to COVID, but some material and analysis was still able to take place during this time. A 12-month no cost extension was granted, to able the PhD student to complete their studies, and interim report was received in June 2022 which showed good progress, and the project has demonstrated the translational advantages and benefits of interrogating disease mechanisms, identified new therapeutic targets and tested novel compounds in the more translationally relevant human Precision Cut Slice platform.

We supported the IGNITE DMD (SGT-001) Gene Therapy programme with Solid Biosciences - we were told gene therapy would not happen in our lifetimes. But we did not accept that. We are pleased to say this gene therapy programme has been tested in clinic in the US. Gene therapy offers hope as a potential treatment for Duchenne. We are extremely proud to have played a part in helping to accelerate the development of gene therapy. In September 2022, Solid announced that it had made a strategic decision to prioritise SGT-003, their next-generation AAV gene therapy candidate over SGT-001 it's first-generation gene therapy candidate. News in January 2024 announced it has been granted orphan drug designation from the FDA for SGT-003 which now furthers their efforts to meet the ongoing challenge of treating this devastating disease as expeditiously as possible, these designations are important milestones, supporting the continued development of next-generation therapies for Duchenne. Solid is now currently in the process of securing approvals from the institutional review boards (IRB) at the clinical trial sites for the planned Phase 1/2 clinical trial of SGT-003 and expects to commence patient screening shortly thereafter. Patient dosing in the trial is expected to commence in mid-to-late first quarter of 2024.

We supported a 5-year period (2015-2020) Lectureship Post (Dr Michela Guglieri) - and we are delighted to report the outcomes of this grant, which was supported by a consortium of seven UK charities, Alex's Wish joined by Duchenne UK, Action Duchenne, Duchenne Research Fund, Duchenne Now, Duchenne UK, Harrison's Fund and Joining Jack to invest a total of £250,000. The Clinical Trials Lectureship grant enabled Dr Michela Guglieri to act 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 research

centres, that ensures trials are run smoothly and safely, and generate good quality data. The project has supported the establishment of a strong clinical research team at the John Walton Muscular Dystrophy Research Centre and of national and international collaborations and networks which will play a key role in ensuring the clinical research in Duchenne Muscular Dystrophy will continue to come to the UK and to establish the UK as an expert and efficient country to deliver best care practice and clinical research. Since May 2017, as well as training and supporting the staff in the clinical research centre, over the course of the grant, Dr Guglieri has led 10 clinical trials in Duchenne, including The FOR DMD Study and The Vision DMD Trial, testing the safety and effectiveness of Vamorolone - a potential drug that researchers hope could offer some of the effects of steroids with fewer side effects. The support from the 7 different charities has not only resulted in significant impact during the years of funding, but also a permanent position for Michela through Newcastle University. In this role, she will continue to work as Clinical Research Lead, supporting clinical research activities as well as national/international collaborations to improve care, treatment and research opportunities for those living with Duchenne. DMD Clinical Trials Lectureship Release

Financial Review
Income from donations and fund-raising activities for the year amounted to £343,744 (2022: £225,821). Bank interest received in the year amounted to £834 (2022: £59).

Expenditure incurred is as shown on the detailed statement of financial activities and included: expenditure on fund-raising activities which amounted to £51,201 (2022: £41,305).

Overheads include payments for administrative services and the management of events and fundraising activities of £66,419 (2022: £51,761) and other costs relating to promotional materials, Trustee expenses, insurance, bank charges, marketing, bookkeeping, and networking events of £28,033 (2022: £13,901).

Payments towards research and clinical trials amounted to £288,109 (2022: £117,000). Overall, there were net outgoing resources for the year of £89,184 (2022: incoming £1,913).

Our Impact
The Trustees are delighted that they have been able to make significant payments during this accountancy period to five projects equating to £288,109 in line with its objectives. We provide project updates as and when they become available on our website alexswish.org and via e-newsletters to our supporters.

Financial Reserves Policy
The Charities SORP requires a charity to state the amount and type of financial reserves it holds, and to compare how the level of those reserves matches up to "The level of reserves the trustees feel as appropriate given their plans for the future activities of the charity". Where it falls short, the trustees need to explain what steps they are taking to rectify the situation. In this context, the charity views financial reserves as those held in its unrestricted funds, the balance of funds stood at £52,592 at the year-end (2022 £142,076). The Trustees establish the appropriate level of unrestricted reserves (over and above those already ring-fenced for plans or known liabilities within restricted and designated Funds) by seeking to ensure that the level of the charity's 'free reserves' meets a chosen benchmark related to the budgeted expenditure for unrestricted activities. The Trustees consider the "free reserves" to be the unrestricted funds not committed or invested in tangible assets. As a result of a full and objective review of its 'free reserves' policy, considering all the risks foreseeable at that point and the charity's approach to their mitigation, the Trustees agreed on 9th February 2023 that £30,000 should be maintained as 'free reserves'. This level has continued to be reviewed for adequacy and robustness to ensure the Charity maintains adequate finances to meet day-to-day operating costs, and we will continue to review this over the coming months. As of 30 June 2023, the Charity's "free reserves" stood at £52,892 (2022: £142,076), resulting in a surplus of £22,892 (2022: surplus of £112,076) when compared with the current benchmark, calculated as £30,000.

Strategic approach and plans
Our strategy is to attract as much funding as possible, through the following core activities:

- Increase our level of income generated each year by building relationships with our existing supporters as well as attracting new supporters to our cause.
- Continue to fund projects that will bring about effective treatments, new technologies, improve care standards, and improve clinical trial capacity in the UK for the Duchenne community and aim to invest £150,000+ minimum per annum.
- Attract new businesses to our cause to ensure we have a pipeline of income scheduled for at least 12 months ahead.
- Develop new and existing fundraising streams and activities, with a view to increasing regular giving to help with the peaks and troughs of fundraising events streams.
- Concentrate on our core events calendar, whilst introducing new events that attract interest from different audiences. Aim to generate 70% profit from our events and attract corporate sponsors to cover event costs.
- Attract businesses who can donate a percentage of their income/sales revenue, Netmetix is a great example of this.
- Increase the number of touchpoints with new and existing supporters to demonstrate the impact made to our beneficiaries and to outline our future goals and fundraising initiatives. This includes our Spring launch and Annual Lunch inviting our supporters along to update them on progress and our plans. We also arrange 1-2-1 meetings and networking events with our business supporters to keep in touch and update them on our progress.
- Develop our relationships with the Trusts and Foundations who have supported so far, and to research new Trusts and Foundations to apply for funding in the future.
- Recruit more ambassadors to our cause, to help spread the word about our work and attract new supporters.

- Find opportunities for our Founder to speak at events to raise the profile of Alex's Wish, about Corporate Social Responsibility as well as give talks about resilience and positive thinking.
- Continue to review operating costs and resources ensuring it is in line with our objectives.
- Raise awareness and increase our visibility across the East Midlands region.

In the coming year we plan to:

Objective 1: To identify, fund and monitor medical research projects, clinical trials, clinical trial capacity opportunities and new technological advances.

- To receive updates on outcomes for projects funded so we can report on the impact those projects have made to help progress our mission. To report on these via our news feeds on our website, our social media platforms, e-newsletters to our supporters, through local press coverage and at our events.

- Continue to work closely with Duchenne UK as a Charity Partner. To seek out and fund new projects that fit with our mission to conquer Duchenne – to improve and extend the lives of everyone affected. Ensuring that our funds are spent effectively and in the right areas to help bring about the best chances of bringing new treatments to market.

Objective 2: To continue lobbying government and other regulators and to engage with media and our supporters to raise awareness of Duchenne Muscular Dystrophy.

- Attend national events and meetings to help lobby MPs and Parliament to bring about new treatments to market as quickly as possible e.g. Vamorolone and Givinostat. To be involved in meetings and activities alongside Duchenne UK that is focussed on improving care standards in the UK.

- Attend Duchenne Parent Days and Conferences held by Duchenne UK to engage with other parents affected by Duchenne Muscular Dystrophy, as well as keep abreast of latest progress made in the field of Duchenne.

- Continue to write press releases and submit to the local press in the East Midlands to help raise awareness about the work we are doing and its impact on the local community / the rest of the UK and to help attract new supporters to our cause.

- Continue to send monthly updates to our supporters via e-newsletters, add newsworthy content to our website and regularly post and grow our supporter base across our social media platforms.

- Organise Supporter events including out annual Spring Launch and our Autumn Lunch to keep in touch with our supporters and guests about the vital work that we do, and how they can continue to help us.

- Continue to attend networking events within the region to build new and foster existing relationships and attract new supporters to our cause and arrange 121's with business supporters on how we can collaborate and foster relationships.

- Continue to speak at community and business events where opportunities to arise.

Objective 3: Fundraise through our flagship events, supporter events and fundraising activities.

- Organise our flagship events: Golf Day, Supercars Event, Football Tournament, Fashion Show collaborating with other local charities, our Annual Fundraising Ball and The Big Christmas Give.

- Support other organisations, groups and individuals who have decided to organise their own events in support of our cause, providing resources and time to support them achieve their fundraising goals.

- To attract supporters to take part in the Prudential Ride London, London Marathon, Sky Dives, Quiz Nights, family-fun walking and running events, challenge events e.g., Zipwire challenges, Sky Dives, Loop the Loop Aerobatic displays, Wing Walks, and Abseil Challenges.

- Retain our existing regular giving supporters and develop new initiatives to grow our regular giving supporter base, through our 'Be More Alex' £7 a month regular giving campaign, our Business Club/Community £75 a month regular subscription in exchange for business benefits such as organising local networking events to bring the local business community together. Continue to support Netmetix who donates a percentage of their income to us every single month and look to attract like-minded business.

- We aim to work within a 30:70 ratio of cost vs. income received from an event to ensure that 70% of what we raise from our events overall goes directly to fund projects to further our mission. We would like to attract more capital through corporate sponsors to cover most/if not all our event costs to help improve this ratio further. We have been successful in attracting corporate sponsors and will continue to build on those relationships.

- Majority of our income raised has been through hosting our own events. Our aim is to continue working with local businesses to take Alex's Wish on as their chosen charity and organise their own events and consider Alex's Wish as their Charity of the Year. This means that 90%+ of the money they give to us as a Charity goes directly to fund projects to further our mission as they do not incur the expenditure that our own fundraising activities require.

- Continue to work closely with the Miss Great Britain partnership who has chosen Alex's Wish as one of their two charities to support and will work closely with the finalists to support with their personal fundraising initiatives.

- Continue to work with The Brothers Trust foundation, St. James's Place Charitable Foundation and With Love, Steph foundation and other local charitable groups, as well as source external support to identify new trusts and foundation opportunities.

- Form strategic alliances and partnerships with organisations such as local sporting clubs, colleges, schools, and corporate businesses.

- Launch a platform to promote our Founder's speaking offering on the topic of resilience and positive thinking, join the Professional Speakers Association and grow our knowledge on how we capitalise on public speaking in the community and at business events through running workshops and talks on this subject to help generate new income stream to Alex's Wish.

Structure, Governance and Management
The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Trustee Recruitment
Trustees will be recruited through recommendations and social media, at our events and through word of mouth. Those expressing an interest will, in the first instance, be met by the Charity Founder, given an overview of the organisation, and encouraged to apply if they are deemed suitable. The Chair and Co-Chair trustees will examine the applications against the most recent skills audit, produce a short list, and invite those on it to submit their references and then attend an interview; the Chair and Co-Chair will conduct the interviews, and make recommendations to the Board. At its next meeting, the Board will review these recommendations, and either ratify or reject. Successful applicants will be asked to complete and sign the declaration of interest form, sign a declaration that they are eligible to serve as a trustee; and agree to the code of conduct. They will then become a trustee of the Board.

Organisational Structure
The organisation is a charitable company limited by guarantee, incorporated on 22 June 2012. The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £10.

The body responsible for management of the Charity is the Board of Trustees of Alex's Wish. The Board meets monthly (and at least ten times per year). The charity's constitution is set out in the Articles of Association, and all Trustees have agreed to this. New Trustees are appointed by the existing Board of Trustees. Trustees give of their time freely and no Trustee remuneration was paid in this year. Details of Trustee expenses and related party transactions are disclosed in the accounts. Trustees are required to disclose all relevant interests and to withdraw from decisions where a conflict of interest arises. None of the Trustees have any interests with the pharmaceutical industry.

We regularly review our stated aims, objectives, and activities to ensure we are working toward our stated purposes. We have referred to the guidance contained in the Charity Commission's general guidance on public benefit under the Charities Act 2011 when setting and reviewing our aims and objectives and in planning our future activities. All our charitable activities focus on improving the lives of those with living with Duchenne Muscular Dystrophy.

Risk Management
The Trustees continue to review the major strategic, business, and operational risks which the charity faces and confirm that systems are in place to enable regular reports to be produced so that the necessary steps can be taken to lessen these risks. In assessing risk, the Trustees recognise that some areas of the work require the acceptance and management of risk if the charity is to achieve its objectives.

Approved by order of the board of trustees on 22 March 2024 and signed on its behalf by:



Mrs E J Hallam – Founder, CEO and Trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF ALEX'S WISH

Independent examiner's report to the trustees of Alex's Wish ('the Company')
I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2023.

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

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

Independent examiner's statement
Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Association of Chartered Certified Accountants, which is one of the listed bodies.

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

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

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



J Petha FCCA
The Association of Chartered Certified Accountants

Sturgess Hutchinson
Chartered Certified Accountants
21 New Walk
Leicester
LE1 6TE

22 March 2024

ALEX'S WISH

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2023

	Notes	2023 Unrestricted fund £	2022 Total funds £
Income and endowments from			
Donations and legacies		43,447	19,652
Charitable activities			
Fund-raising activities		300,297	206,169
Investment income	2	834	59
Total		344,578	225,880
Expenditure on			
Charitable activities			
Expenditure on charitable events		51,201	41,305
Administrative services		66,419	51,761
Payments for medical research, clinical posts, and new technologies		288,109	117,000
Other expenses		28,033	13,901
Total		433,762	223,967
NET INCOME/(EXPENDITURE)		(89,184)	1,913
Reconciliation of funds			
Total funds brought forward		142,076	140,163
Total funds carried forward		52,892	142,076

The notes form part of these financial statements

ALEX'S WISH

BALANCE SHEET
30 JUNE 2023

	Notes	2023 Unrestricted fund £	2022 Total funds £
Current assets			
Debtors	7	12,979	12,925
Cash at bank and in hand		54,949	138,717
		67,928	151,642
Creditors			
Amounts falling due within one year	8	(15,036)	(9,566)
Net current assets		52,892	142,076
Total assets less current liabilities		52,892	142,076
NET ASSETS		52,892	142,076
Funds	9		
Unrestricted funds		52,892	142,076
Total funds		52,892	142,076

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 June 2023.

The members have not required the company to obtain an audit of its financial statements for the year ended 30 June 2023 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

(a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and

(b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 22 March 2024 and were signed on its behalf by:



Mrs E J Hallam, Founder, CEO and Trustee

The notes form part of these financial statements

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023

1. Accounting policies

Basis of preparing the financial statements
The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) '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)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Income
All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received, and the amount can be measured reliably.

Expenditure
Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Taxation
The charity is exempt from corporation tax on its charitable activities.

Fund accounting
Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Hire purchase and leasing commitments
Rentals paid under operating leases are charged to the Statement of Financial Activities on a straight-line basis over the period of the lease.

Pension costs and other post-retirement benefits
The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. Investment income

	2023	2022
	£	£
Deposit account interest	834	59

3. Net income/(expenditure)

Net income/(expenditure) is stated after charging/(crediting):

	2023	2022
	£	£
Other operating leases	3,570	-

4. Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year ended 30 June 2023 nor for the year ended 30 June 2022.

Trustees' expenses

There were no trustees' expenses paid for the year ended 30 June 2023 nor for the year ended 30 June 2022.

5. Staff costs

	2023	2022
	£	£
Wages and salaries	64,946	50,284
Other pension costs	1,473	1,477
	66,419	51,761

The average monthly number of employees during the year was as follows:

	2023	2022
Administration	3	2

No employees received emoluments in excess of £60,000.

6. Comparatives for the statement of financial activities

	Unrestricted fund
	£
Income and endowments from	
Donations and legacies	19,652
Charitable activities	
Fund-raising activities	206,169
Investment income	59
Total	225,880
Expenditure on	
Charitable activities	
Expenditure on charitable events	41,305
Administrative services	51,761
Payments for medical research, clinical posts, and new technologies	117,000
Other expenses	13,901
Total	223,967
NET INCOME	1,913
Reconciliation of funds	
Total funds brought forward	140,163
Total funds carried forward	142,076

7. Debtors: amounts falling due within one year

	2023	2022
	£	£
Trade debtors	3,290	729
Prepayments and accrued income	9,689	12,196
	12,979	12,925

8. Creditors: amounts falling due within one year

	2023	2022
	£	£
Social security and other taxes	655	-
Accruals and deferred income	14,381	9,566
	15,036	9,566

9. Movement in funds

	At 1.7.22	Net movement in funds	At 30.6.23
	£	£	£
Unrestricted funds			
Unrestricted funds	142,076	(89,184)	52,892
TOTAL FUNDS	142,076	(89,184)	52,892

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Unrestricted funds	344,578	(433,762)	(89,184)
TOTAL FUNDS	344,578	(433,762)	(89,184)

Comparatives for movement in funds

	At 1.7.21	Net movement in funds	At 30.6.22
	£	£	£
Unrestricted funds			
Unrestricted funds	140,163	1,913	142,076
TOTAL FUNDS	140,163	1,913	142,076

Comparative net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Unrestricted funds	225,880	(223,967)	1,913
TOTAL FUNDS	225,880	(223,967)	1,913

10. Related party disclosures

There were no related party transactions for the year ended 30 June 2023.

ALEX'S WISH

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2023

	2023 £	2022 £
Income and endowments		
Donations and legacies		
Donations	43,447	16,843
Grants	-	2,809
	43,447	19,652
Investment income		
Deposit account interest	834	59
Charitable activities		
Fund-raising activities	300,297	206,169
Total incoming resources	344,578	225,880
Expenditure		
Charitable activities		
Annual Golf Day	4,538	5,437
Prudential Ride London	945	4,482
Annual Fundraising Ball	20,807	15,829
Masquerade Ball (Virtual)	-	473
Business Club	429	165
London Marathon	3,531	700
Supercars Charity Event	6,696	761
Charnwood Forest Cycle Ride	-	1,015
'Be More Alex' regular giving campaign	783	869
Abseil Charity Event	1,145	2,475
Annual 'Supporters Thank You' Autumn Lunch	5,009	4,107
Miss Great Britain Finals Event	639	524
Skydiving Events	2,768	900
Football Tournament Event	448	1,267
Tabletop Sale	-	150
Loop the Loop Challenge with AeroSparx	2,218	1,938
Stan Hulme's Nordic Challenge	109	175
Other sundry event costs	150	38
Big Give Christmas Challenge	60	-
Fashion Show	100	-
Spring Launch	826	-
	51,201	41,305
Support costs		
Management		
Wages	64,946	50,284
Pensions	1,473	1,477
Office Rent	3,570	-
Insurance	730	445
Business Development & Networking Events	5,763	6,204
Postage and stationery	213	7
Promotional materials	4,907	992
Office equipment	2,092	-
Bookkeeping and legal fees	278	237
Travel and subsistence	1,824	1,436
Bank charges	358	361
Staff Training and Welfare	366	159
Carried forward	86,520	61,602

ALEX'S WISH

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2023

	2023 £	2022 £
Management		
Brought forward	86,520	61,602
Computer and software costs	5,142	3,700
Website and email marketing	450	360
Accountancy	2,340	-
	94,452	65,662
Other		
Payments for Medical Research, Clinical Posts, and New Technologies	288,109	117,000
Total resources expended	433,762	223,967
Net (expenditure)/income	(89,184)	1,913

ALEX'S WISH

England & Wales - Charity number 1148845

Accounts

Alex's Wish

Company Limited by Guarantee

Trustees report and unaudited financial statements

Registered company number 08116159

Registered charity number 1148845

30 June 2022

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Legal and administration information

Trustees & directors	Mr AR Hallam Mrs EJ Hallam Mr CR Everard Mrs J Edwards Ms G Wright Ms S Barnett Ms AL Slack Mr S Jesrani Mr TW Carter
Company No	08116159
Charity No	1148845
Website:	www.alexswish.org
Registered office	The Old Vicarage High Street Syston Leicestershire LE7 1GP
Independent Examiner	HSP Tax & Accounts Ltd Whiteacres Cambridge Road Whetstone Leicestershire LE8 6ZG
Bankers	National Westminster Bank plc

Trustees' report

The Trustees present their report and unaudited financial statements for the year ended 30 June 2022.
The Trustees, who are also Directors of the charitable company for the purposes of the Companies Act, and who served during the year and up to the date of signature of the financial statements were:

- Emma Hallam, Founder and Chief Executive Officer
- Andy Hallam, Founding Trustee
- Stephen Dean, Chair and Trustee (Resigned 1st September 2021)
- Alexandra Slack, Chair and Trustee (Appointed as Chair 1st September 2021)
- Chris Everard, Trustee
- Rachel Hargrave, Trustee (Resigned 1St December 2021)
- Janine Edwards, Trustee
- Glynis Wright, Trustee
- Sally Barnett, Trustee
- Sandesh Jesrani, Treasurer
- Kelly Boorman, Trustee (Resigned 1 October 2022)
- Thomas Carter, Trustee

The Trustees confirm that the annual report and financial statements of the charitable company comply with the current statutory requirements and the provisions of the Statement of Recommended Practice (SORP) Accounting and Reporting by Charities.

Registered Office: The Old Vicarage, High Street, Syston, Leicestershire, LE7 1GP

Website: **www.alexswish.org**

Registered Charity No: 1148845

Scientific Advisory Board. We work closely with Duchenne UK as their Charity Partner and as such most projects that we fund are co-funded alongside them. All projects put forward to us for potential funding go through their rigorous Scientific Advisory Board, which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy. It includes the different skills of doctors, scientists, and drug developers so that each project is asked the right questions: Is this good science? Can this be taken into clinic? What hurdles exist? Is this replicated anywhere else? Duchenne UK's advisory board consists of:

- Professor Dame Kay Davies
- Dr. Eric Hoffman
- Dr. Annemieke Aartsma-Rus
- Dr. John Bourke
- Professor Dirk Fischer
- Dr. Dada Pisconti
- Dr. Valerie Riccoti
- Frank Robertson
- Dr. Olivier M Dorchies
- Dr. Manuela Corti

Professional Service Providers
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Whiteacres, Cambridge Road
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Leicester LE8 6ZG

Bankers
National Westminster Bank plc
5 The Parade, Oadby, Leicester LE2 5NT

Alex's Wish would like to thank its Trustees, employees, service providers, and supporters for kindly giving their time and expertise to grow the charity.

Statement from the CEO and Charity Founder, Emma Hallam

In September 2022, Alex's Wish celebrated it's 10-year milestone – something we are incredibly proud of. We launched Alex's Wish in late 2012 after our son, Alex, was diagnosed with Duchenne Muscular Dystrophy. When the diagnosis was confirmed, we were absolutely devastated as doctors told us there was NO CURE and NO TREATMENTS available other than steroids which cause serious side-effects and, at best, would help delay the onset of his condition by two years at most.

Duchenne is a life-changer. It affects every single day of your life as you must be prepared for ever-changing challenges that affect your child's day to day activities. Duchenne is a progressive, muscle wasting disease. It is relentless affecting every single muscle in the body. One day your child may not be able to walk, may not be able to lift a cup to their mouth, may not be able to access their friends' houses anymore. We felt overwhelmed and terrified of what the future held for our son, living in fear of the next stage of progression and wondered how we would cope.

At the time of diagnosis, we quickly realised we have no time to waste. We investigated the latest scientific research and understood that without ongoing funding this work would not continue. We set-up Alex's Wish, a charity based in the heart of Leicestershire, as we knew we would attract interest and support from the community across the East Midlands and beyond bringing in additional funds to what was already being raised. We do not duplicate efforts of other charities working in this field instead our focus is to **drive additional funds** allowing us to co-fund scientific projects with other charities like Duchenne UK.

The science is at a very exciting time; a time of hope of new treatments being just around the corner. We were told that Gene Therapy wouldn't happen in our son's lifetime. However, we've seen the first Duchenne patient being dosed in a Gene Therapy trial in the UK.

The research we have funded is bearing fruit with Santhera Pharmaceuticals' Vamorolone - a new steroid alternative without the nasty side effects of traditional steriods - has applied for marketing authorisation (approval for use in the UK). This will help every single patient living with Duchenne and something we are incredibly proud of.

We've seen the development of new prototype technologies; The Smart Suit and The DREAM Wheelchair starting to emerge and showing great promise.

A clinical trial which Alex Hallam has been on for the past 4 years, called **Givinostat run by Italfarmaco** announced in the Summer of 2022, that the drug is working to help slow down disease progression. This is great news for the Duchenne community as a whole and brings with it so much hope for the future. For more details, visit https://alexswish.co.uk/italfarmaco-announces-positive-topline-data-from-phase-3-trial-showing-positive-benefits-of-givinostat-in-duchenne/

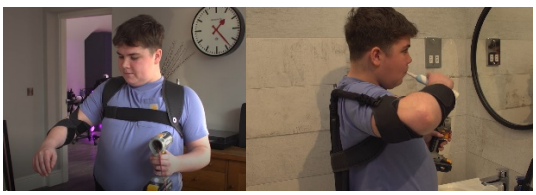
With all this progress, we cannot help but feel incredibly hopeful that more effective treatments are just around the corner to help everyone living with Duchenne. The hard work is paying off, but we must continue our journey to find new discoveries to slow down and ultimately stop muscle wasting.

We are delighted with our progress to date and excited about the times ahead. We are incredibly grateful to our wonderful supporters who have come on this journey with us so far. We would like to say a **very special thank you** to the following people and organisations.

- Duchenne UK, a charity run by two mums (Emily Crossley and Alex Johnson) who have sons Eli and Jack who also live with Duchenne, for their incredible work and by collaborating with them, we ensure we only ever invest in the best science and technologies available.
- Our fundraising team Zoe Edwards, Heidi Eastell and Heather Stone for their enthusiasm, hard work and support. They contribute significantly to the day-to-day running of the Charity and its success.
- Our dedicated Trustees for their continued support, help in running the charity, providing a great platform to discuss future goals and initiatives, much-valued feedback and for their introductions to new supporters.
- To those businesses who offer pro-bono work: HSP Tax for producing our annual accounts and reporting, Flexpress for print and production, New English Design for website hosting, Winstanley House for hosting our Ethical Business Club events at their venues, Delta Global for our promotional bags, Fashion UK for our branded t-shirts, Brooksure Insurance for our annual insurance and Hallam Read who gave us office space at zero cost (until February 2023) to keep our running costs low, and to all those suppliers who work with us providing services at reduced costs.
- Every business, club and supporter who has either chosen us as their Charity of the Year, sponsored our events, organised events for us, attended our flagship events and taken part in various challenges, donated items and experiences for our fundraising auctions and raffles, our ethical business club members and to our ambassadors who shout from the rooftops about the work we do. There are too many to list individually, however we list all businesses who support our cause on our website, and feature supporter stories across our social media sites and through our news stories which are also released to the local media.
- To our major donors and event sponsors for their financial contributions during period, including (but not limited too) The Brothers Trust, St. James Place Charitable Foundation, With Love, Steph Foundation, Netmetix, Miss Great Britain, Spirit Healthcare, Janine Edwards Wealth Management and Strategic Solutions.

In this financial year, we have invested £117,000 in four projects (2020/21 £62,142 in three projects):

- **Project 1 (£87K) – The Smart Suit revolutionary technology for upper body strength and function** in children living with Duchenne. This Suit – funded by players of People's Postcode Lottery, Duchenne UK, Alex's Wish and Joining Jack – helps disabled people keep the use of their aims. The project officially started in July 2022, and a project manager was appointed. An industry partner PA Consulting has been contracted to help design and build the suit prototype. Medipex is now working on the commercialisation strategy. At the time of writing this report, the prototype has appeared on ITV Central, Sky News, GB News and BBC News and is showing great promise. Here are a few photos of Alex Hallam trialling out the prototype. We will continue to support this ongoing work.



- **Project 2 (£20K) – Gene Therapy Grant Call -** We've seen incredible progress in gene therapy for Duchenne, but challenges still lie ahead. One of these challenges involves looking at how the immune system in some patients reacts to

gene therapies. Some people have antibodies to the gene therapy viral vector, the vessel in which the genetic material is delivered to muscles, so they don't qualify for this treatment. In addition, even those patients without antibodies will develop them after receiving gene therapy, so they won't be able to have the treatment more than once. We are however, now seeing novel, promising approaches, leading the way for cell-based therapies and new gene therapies that use non-viral vectors. This vital research will help to accelerate its progress so that one day everyone with Duchenne can have gene therapy treatments safely and effectively. The grant call was launched in October 2022, and the expression of interest stage closed on 6th December 2022. The next stage is to identify which projects to progress to the full application stage.

- **Project 3 (£5K) – MyoGene gene editing therapy to accelerate the investigations needed to translate stem cell-based approaches or gene therapies into clinical trials or application in patients.** The funding for this project will support testing a gene-editing therapy for Duchenne in preclinical models.

- **Project 4 (£5K) – Antifibrotic screening platform with Professor Diaz Manera** (a new molecular biology technique which enables them to look inside muscle cells for Duchenne patients. This will help them to understand which treatments are most effective in preventing fibrosis, a process which happens when muscle cells die and are replaced by fatty tissue. Fibrosis can lead to failure of the heart and respiratory muscles, which is the most common cause of death in adults with Duchenne. Professor Diaz Manera and his team have already analysed nearly 200 potential drugs and identified ten promising candidates for further investigation. The researchers will combine this drug screening approach with examining the Duchenne muscle cells. Combining these two approaches could provide the evidence needed to take promising anti-fibrotic medicines into clinical trials. While gene therapies could be transformative for people living with Duchenne, the progressive nature of the disease limits their impact. Combining gene therapies with drugs that could reduce muscle deterioration, such as anti-fibrotics, could help to maximise the effect of these treatments. Anti-fibrotics could also be used to treat patients who are not eligible for gene therapy, and for those in the later stages of the disease.

Our revised target for our next financial year, is to raise £300,000 (1st July 2022 - 30th June 2023) and, at the time of writing this report, we stand in good stead to achieving this as £200,000 has already been raised.

Of this, £65K has already been invested in The DREAM Wheelchair. For our children, a wheelchair makes all the difference to their independence. But the design and functionality of wheelchairs has changed little in 15 years, even when the design conscious and technology driven world has transformed so much else. In 2017, in partnership with Whizz-Kidz, Duchenne UK won a £1M grant to develop a new wheelchair. The project was designed to bring wheelchairs into the 21st century. Getting up a kerb, seeing what is behind you, even having somewhere to put your phone - things the rest of us barely notice in our lives are major tasks for young wheelchair users. Three years on, with a prototype built, we are working on how we can bring this chair to market, at an affordable rate.



As at writing this report, March 2023, we can report that we have £80,000 funds held to support exciting projects to further our mission. These include the continuation of The Smart Suit, The DREAM Wheelchair, an at-home physiotherapy app and a weight management programme.

We are incredibly positive about the future and Alex's Wish gives us hope. Duchenne Muscular Dystrophy is part of our lives, not out of choice, but we will make it as best as we can, and we will never stop our journey to conquering Duchenne. We could not have done our work without the support of our army of supporters, the charitable foundations who have supported us, the local business community, business sponsors, our fundraising team, ambassadors and our dedicated trustees and we would like to express our gratitude and thanks to every single one of them.

Emma Hallam
Charity Founder

About Duchenne Muscular Dystrophy
Duchenne Muscular Dystrophy is a devastating life-shortening genetic disease that affects 1 in every 3,500 boys born (it also affects girls who account for 1% of all those diagnosed). It is caused by a mutation in the gene that encodes for dystrophin, a protein that is essential to the proper functioning of our muscles. Without dystrophin, muscles are not able to function or repair themselves properly. The loss of muscle then results in a loss of strength and function.

Duchenne can be passed from parent to child, or it can be the result of random spontaneous genetic mutations, which may occur during any pregnancy. In fact, about one out of every three cases occurs in families with no previous history of Duchenne. In other words, it can affect anyone, and crosses all races and cultures. The average age of a Duchenne diagnosis is around 4 years old. Many times, there will be delays in early developmental milestones such as sitting, walking, and/or talking. Speech delay and/or the inability to keep up with peers will often be the first signs of the disorder.

Duchenne progresses differently for every person. Even siblings with the same mutation may have a very different progression of symptoms. Muscle loss is first noticed in childhood, with loss of strength, function, and flexibility in the hips, thighs, shoulders, and pelvis. In teens these losses begin progressing to the arms, lower legs, and trunk. Because there is also an absence of dystrophin in the muscles of the heart and lungs, heart function and breathing are also affected. In addition, some people can have issues with learning and behaviour resulting from a lack of dystrophin in the brain.

The progression of symptoms through Duchenne are on a spectrum from late onset/very mild symptoms to early onset/severe symptoms. Regular visits with a neuromuscular team help to monitor the progression of disease and how it can best be treated along the way. With improved care more people with Duchenne are living into their 30s and beyond. With clinical care continuing to improve, as well as clinical trials, research, and therapies on the horizon, we are hoping to enhance the quality of life and extend the lives of those affected.

A carrier of Duchenne is a woman who has a mutation in one of her two copies of the dystrophin gene. Carriers have an increased chance of having sons with Duchenne and daughters who are carriers. Female carriers are usually not affected with Duchenne because they make enough of the dystrophin protein. However, they can have some symptoms of Duchenne such as muscle weakness and heart problems. Though it is rare, some females can have the classic symptoms of Duchenne.

Duchenne in numbers
- 1 of the most serious genetic diseases in children.
- 1 in every 3,500 boys born will have Duchenne.
- 2,500 boys affected in the UK.
- 300,000 boys affected worldwide.
- 2 families per week receive diagnosis in the UK.
- 90% of boys will require the use of a wheelchair by the age of 12.

What we are doing about it
We are committed to continuing to drive momentum to deliver treatments to help **THIS generation** of those with Duchenne. We have invested £844K in scientific research, clinical trials, funded clinical posts ensuring patients living in the UK can access trials, as well as new technological advances. We have an innovative approach to funding. Not only do we fund basic research, but we fund clinical trials and the doctors and nurses in the UK to deliver those trials.

Our Vision

Our Vision is a world without Duchenne Muscular Dystrophy. We want a future that stops the devastating
impact Duchenne has on our children and young adults, a future where they can grow and prosper and fulfil their dreams. A life where they can enjoy every day without the fear of the progression this muscle wasting disease has on their bodies. A future without Duchenne would be a bright and happy future for all those affected. We need to act quickly to save this generation. Doing nothing is not an option. Our boys and their families need to live without fear and have hope for the future.

Our Mission

Alex's Wish was set-up by a family affected by Duchenne, who understand first-hand the impact this condition has on their child and the family. As a family we are taking part in clinical trials ourselves as we understand the importance of clinical trials and how they will help being effective treatments to market. We have one clear mission; to conquer Duchenne soon. We are doing this by funding medical research that's focussed on getting treatments to those affected now as well as pushing for effective treatments in the future. Our ultimate focus is to extend/improve the lives of those living with Duchenne, to halt or reverse the effects of muscle wasting.

Charities like ours fund half of all medical research in the UK – to the tune of £1.7 billion. Today, 1 in 4 people choose to support medical research charities like ours, and for this we are so incredibly grateful.

Our Progress

- Continued to increase funds raised each year and have continued to raise funds despite the impact of the Pandemic in 2020 and 2021.
  - Y1 - 1 July 2012 to 30 June 2013 - £53,025
  - Y2 – 1 July 2013 to 30 June 2014 - £83,962
  - Y3 – 1 July 2014 to 30 June 2015 - £134,263
  - Y4 – 1 July 2015 to 30 June 2016 - £124,885
  - Y5 – 1 July 2016 to 30 June 2017 - £157,626
  - Y6 – 1 July 2017 to 30 June 2018 - £197,688
  - Y7 – 1 July 2018 to 30 June 2019 - £218,518
  - Y8 – 1 July 2019 to 30 June 2020 - £201,178
  - Y9 – 1 July 2020 to 30 June 2021 - £129,778 (reduction in funds raised due to the COVID Pandemic)
  - Y10 – 1 July 2021 to 30 June 2022 - £223,012

- As a Charity we have again made use of the government's furlough scheme and placed our employees onto part-time furlough during the Pandemic which has enabled us to protect those jobs whilst giving them job security and peace of mind.

- We continue to increase funding into innovative projects year on year and invested a total of £779,465 towards research, clinical trials, and increasing clinical trial capacity (this is up to 30th June 2022).
  - Y2: £28,415
  - Y3: £74,100
  - Y4: £73,661
  - Y5: £92,862
  - Y6: £112,143
  - Y7: £144,142
  - Y8: £75,000
  - Y9: £62,142
  - Y10: £117,000
  - In addition, and as at writing this report in March 2023, we have invested a further £65,000 into The DREAM Wheelchair project and have an additional £80,000 due to be invested imminently.

Our Charitable Objectives

1. The principal objects of the charitable company are the relief of sickness and the preservation of good health by supporting scientific research into the improved diagnosis, prevention, or treatment of Duchenne Muscular Dystrophy. This is to be achieved by:
   a) Extending the current scope of drugs / treatments so that they will help all children with Duchenne Muscular Dystrophy.
   b) Fund first stage clinical trials that provide the safety and efficacy of some of these treatments and then progress this into larger scale production.
   c) Fund the completion of scientific work already begun, to bring it to clinical trials, and fund other forms of treatment that will work on all children regardless of their genetic mutation.
   d) Fund studies that will help bring about data and information to help decision makers make decisions on which treatments to bring to market.
   e) Fund The Newcastle Plan – there is an increasing community wide focus on clinical trial capacity in the UK and Treat-NMD has co-ordinated and organised a national meeting in Newcastle concerning the apparent lack of capacity for trials in Duchenne. This brought together 75 stakeholders representing patient organisations, clinical experts, the pharmaceutical industry, as well as the National Institute for Health Research (NIHR), to develop a strategy to improve capacity and better utilise existing resources. All stakeholders contributed to shaping 'The Newcastle Plan' and concluded that the UK must maintain its place as one of the 'go to' countries for clinical trials in Duchenne, posting a five-year objective to ensure that all potential children and adults with Duchenne, have access to clinical trial research opportunities.

2. Advance the education of the general public, in all areas relating to Duchenne Muscular Dystrophy by disseminating information on the disease and its treatments and cures. To:
   a) Disseminate information using online and offline materials, including the charity's website www.alexswish.co.uk and our World's Strongest Boys video https://youtu.be/0uxxh3xk0_g
   b) Running events and fundraising activities and promoting our work on social media:
      Facebook https://www.facebook.com/alexswishcharity1
      Twitter https://twitter.com/alexswish
      You Tube https://www.youtube.com/channel/UCU-RRlMhQmkhBhNyIsS6hZA
      Linked In https://www.linkedin.com/company/9202750/admin/
      Instagram https://www.instagram.com/alexs_wish/
   c) We have built great relationships with the local media outlets in our region including ITV Central and BBC East Midlands and regularly generate news articles and updates in local newspapers, including The Leicester Mercury and The Loughborough Echo and local magazines posted through doors. We also appear regularly on the local radio stations including BBC Radio Leicester to raise awareness about Duchenne and the impact this has on families living with it.
   d) Talking and presenting at various events on Corporate Social Responsibility, the impact of living with Duchenne Muscular Dystrophy, About Alex's Wish and Resilience – it is important our personal story is shared amongst others.
   e) Participate in alliances and liaise with the Government to inform policy makers and other stakeholders about the work of the charity, the nature of the disease and potential treatments and cures.

Our Grant Making Policy and Collaboration

The Charity has established its grant making policy to achieve its objectives for the public benefit to find a cure
for Duchenne Muscular Dystrophy and to slow down the rate of progression by maintaining muscle strength

for longer leading to increase life expectancy as well as a better quality of life.

We only want to fund great science – projects that can improve the knowledge base and bring treatments that can reach the clinic and improve the lives of boys with Duchenne Muscular Dystrophy in many ways. We want to fund new technologies that will go on to help those affected by Duchenne, by making the world accessible to them.

We formed a partnership with Duchenne UK. Duchenne UK share the same mission and objectives as Alex's Wish and are also a parent-led charity. As a Charity Partner to Duchenne UK, we receive projects that require co-funding. All such projects have been reviewed extensively by their Scientific Advisory Board which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy. They bring with them a wide range of essential skills and knowledge basis including scientific, clinical and drug discovery and development. When scientists approach Duchenne UK with their ideas for new research projects it is the SAB who apply their experience and expertise to test these ideas, helping to refine them, if necessary, in order that Duchenne UK can make informed decisions on funding. Alex's Wish Trustees review all projects put forward before deciding upon specific projects to fund.

We also work with Solid Biosciences to help progress their Gene Therapy programme and this work is now progressing into clinical trials and is showing great promise.

We have worked with Muscular Dystrophy UK to co-fund research and clinical trials. Alex's Wish is part of the Duchenne Forum, a partnership between six UK Duchenne-led charities to help accelerate progress in the search for effective treatments and eventually cures. The partnership is supporting seven pioneering Duchenne research projects committing to £840,000 over a four-year period.

We have worked with Action Duchenne and co-fund projects as such as the Repurposing Cancer Therapeutic drug called Dasatinib – a drug commonly used to treat leukaemia.

We regularly send updates on project performance and outcomes to our supporters through an e-newsletter as well as publish updates on our social media channels, news articles on our websites and submit press releases to the local media companies. We have appeared on BBC East Midlands Today and ITV Central.

Financial Review
Income from donations and fund-raising activities for the year amounted to £223,012 (*2021: £129,778*). Bank interest received in the year amounted to £59 *(2022: £10).*

Expenditure incurred is as shown on the detailed statement of financial activities and included: expenditure on fund-raising activities which amounted to £41,305 *(2021: £7,666)*.

Overheads include payments for administrative services and the management of events and fundraising activities of £51,761 (23% of total income) *(2021: £45,386; 35% of total income)* and other costs relating to promotional materials, Trustee expenses, insurance, bank charges, marketing, bookkeeping, and networking events of £13,901 (*2021: £7,451)*.

Payments towards research and clinical trials amounted to £117,000 *(2021- £62,142)* see breakdown below. Overall, there were net incoming resources for the year of £1,913 (*2021: £31,503)*.

Our Impact
The Trustees are delighted that they have been able to make payments during this accountancy period to four projects equating to £117,000 in line with its objectives. We provide project updates and when they become available on our website. Please visit www.alexswish.co.uk for more details.

Our Major Achievements

- Co-funded 33 projects across a broad-spectrum from early-stage research through to clinical trials, supported five clinical posts to support clinical trial development and invested in new technologies. Here are some examples of the work we have funded to date.
- **We supported a Lipid Nanoparticles (LNPs) technology used in COVID-19 vaccine to see whether it could be used to help in gene therapy treatments for Duchenne.** Lipids are naturally occurring small fatty molecules that exist within the body, and nanoparticles refers to their small size. LNPs are currently being used as a key component in the Pfizer/BioNTech and Moderna COVID-19 vaccine. Several clinical trials of gene therapy are now underway in Duchenne using harmless viruses, called AAVs, to deliver synthetic gene to replace the faulty dystrophin gene in Duchenne. The early data looks promising. But there are some challenges in getting this treatment to the entire Duchenne population, mainly because some patients will have pre-existing antibodies to the virus and so will not currently be able to have the treatment. There are also difficulties in transferring the genes from the viruses into muscle cells. This study aims to address some of these challenges by exploring LNPs as a method of delivering gene therapy. The study is called 'mRNA Targeted Therapeutics for Duchenne Muscular Dystrophy' and will be led by Professor Shenhav Cohen at Technion Institute of Technology, Israel, in partnership with Professor Aartsma-Rus at Leiden University Medical Center and Professor Peer at Tel Aviv University. LNPs can be filled with a variety of materials, including genetic material. Because LNPs are made of naturally occurring lipids, they should not cause an immune response. They also have a good safety profile for use in humans. This study will explore whether a larger dystrophin construct can be carried by the LNPs. The dystrophin gene is the largest gene in the body, but in current gene therapy trials, a shortened construct must be used. Our current understanding of the impact of shortened dystrophin on long-term muscle function is limited, but using a longer gene could lead to better muscle function. The research group plans to engineer the LNP surface such that the LNP will effectively fuse with muscle and deliver its cargo. This research is currently in very early stages. If the researchers can show that this method can effectively deliver genetic material into muscles using a mouse model of DMD, they would have a high chance of receiving a much larger grant for further research. The 1-year report was received in May 2022, and highlighted the need for an extension, which was granted. The project team successfully completed the preparation of the nanoparticles; however they were delayed in starting the animal studies, which is now underway.
- **We Invested in a pioneering Pluripotent Stem Cell Therapy 'Altering the muscle environment to influence stem cell behaviour' at The University of Minnesota** which is looking at regenerating muscle in Duchenne patients with stem cells. Stem cells are a potentially exciting approach to generate new healthy muscle in patients with Duchenne. The stem cells we are looking at are called human induced pluripotent stem cells (iPSCs). These cells replace the diseased muscle tissue with stem cells that can create healthy myofibers which are able to regenerate. The aim of this project is to produce and test these stem cells to get the preclinical data required to progress to a clinical trial. The team will use our grant to test several things including what dosing should be used and the safety and toxicity. If the project is successful, the group will commence planning for a Phase I Clinical Trial to start testing this approach on patients. This project is progressing at pace, and the final IND enabling experiences are on track to be completed by March 2023, with plans to move to the clinic in the second half of 2023.
- **We support a study that is paving the way for improved detection of heart disease in female carriers of Duchenne with De Lee Borthwick and Dr John Bourke at Newcastle University** – following this investment, we are pleased to say that this project has improved understanding of heart muscle disease in female carriers, paving the way for further research. Women and girls

who carry a mutated Duchenne gene (carriers) can sometimes show mild symptoms of the diseases. Duchenne carriers are at risk of developing cardiomyopathy, which affects the ability of the heart to pump blood around the body. Currently Duchenne female carriers are advised to have their hearts checked every 3-5 years by taking scans such as ECG, echocardiogram, or MRI. However, quicker, and more cost-effective ways to detect heart problems would prevent late diagnosis and enable earlier treatment. De Borthwick and Bourke examined the heart tissue of patients and used this to identify molecules in the blood that could act as biomarkers (indicators of damage to the heart). This study has now come to a close, and the preliminary data shows these biomarkers have the potential to detect early cardiomyopathy in a way that is fact, reliable and cost-effective. The biomarkers need to be tested in cohorts of female carriers, as well as make Duchenne patients, to be fully validates. However, this pilot project has laid vital foundations for future research to improve the speed of diagnosis and treatment of cardiomyopathies.

- **We helped fund a PhD post at The John Walton Muscular Dystrophy Research Centre at Newcastle University** specifically to look at the FOR-DMD Study (finding the optimum Steroid regime for boys living with Duchenne) supervised by Dr Michela Guglieri. The PhD post will ensure that the data generated by the FOR-DMD study will be used to address new clinical and research questions.
- **We are helping improve the success rate of clinical trials (PC Slices)** this project is working with Professor Mann and Dr Borthwick from the Newcastle Fibrosis Research Group in the University Biosciences Institute. We had some devastating news at the end of 2019: the early termination of a clinical trial run by Wave Life Sciences. The news was a big blow, not least because early data in animals had shown that the drug was effectively producing dystrophin. How could a trial that showed such a promise in animal models not deliver results in humans? Early-stage tests are done on mice with Duchenne and then transferred to trials in people – but there is uncertainty whether a drug might behave the same in the human body. We want to stop this. That's why we supported this project, which has the potential to help us understand, at a much earlier stage of research, whether a medicine will help treat Duchenne patients. The project has been hit by a reduction in elective surgeries and heart transplants due to COVID, but some material and analysis was still able to take place during this time. A 12-month no cost extension was granted, to able the PhD student to complete their studies, and interim report was received in June 2022 which showed good progress, and the final report is expected in January 2023.
- **We supported the SGT-001 /IGNITE DMD Gene Therapy programme with Solid Biosciences** – we were told gene therapy would not happen in our lifetimes. But we did not accept that. We are pleased to say this gene therapy programme has been tested in clinic in the US. Gene therapy offers hope as a potential treatment for Duchenne. We are extremely proud to have played a part in helping to accelerate the development of gene therapy. In September 2022, Solid announced that it had made a strategic decision to prioritise SGT-003, their next-generation AAV gene therapy candidate over SGT-001 it's first-generation gene therapy candidate. Solid intends to complete current ongoing preclinical and manufacturing activities so that they can reactivate the program in the future, if desired. Solid now remains on track for an anticipated IND submission for SGT-003 in mid-2023, they will continually evaluate the two programs, and believes that this is the right opportunity to put all of Solid's Duchenne efforts behind what we believe to be a best-in-class gene therapy candidate. We will continue to follow and report data from patients who were treated in IGNITE DMD, the Phase I/II trial of SGT-001 as we believe it will continue to build on the benefit Solid's nNOS micro dystrophin can offer to patients.
- **We supported a 5-year period (2015-2020) Lectureship Post (Dr Michela Guglieri)** – and we are delighted to report the outcomes of this grant, which was supported by a consortium of seven UK charities, Alex's Wish joined by Duchenne UK, Action Duchenne, Duchenne Research Fund, Duchenne Now, Duchenne UK,

Harrison's Fund and Joining Jack to invest a total of £250,000. The Clinical Trials Lectureship grant enabled Dr Michela Guglieri to act 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 research centres, that ensures trials are run smoothly and safely, and generate good quality data. The project has supported the establishment of a strong clinical research team at the John Walton Muscular Dystrophy Research Centre and of national and international collaborations and networks which will play a key role in ensuring the clinical research in Duchenne Muscular Dystrophy will continue to come to the UK and to establish the UK as an expert and efficient country to deliver best care practice and clinical research. Since May 2017, as well as training and supporting the staff in the clinical research centre, over the course of the grant, Dr Guglieri has led 10 clinical trials in Duchenne, including The FOR DMD Study and The Vision DMD Trial, testing the safety and effectiveness of Vamorolone – a potential drug that researchers hope could offer some of the effects of steroids with fewer side effects. The support from the 7 different charities has not only resulted in significant impact during the years of funding, but also a permanent position for Michela through Newcastle University. In this role, she will continue to work as Clinical Research Lead, supporting clinical research activities as well as national and international collaborations to improve care, treatment and research opportunities for people living with Duchenne muscular dystrophy. https://alexswish.co.uk/support-from-alexs-wish-helps-fund-duchenne-muscular-dystrophy-dmd-clinical-trials-lectureship/

- **We supported a Heart Study (Arrythmias) study with Professor John Bourke at Newcastle University -** all patients with Duchenne will ultimately be affected by progressive cardiomyopathy and as Duchenne patients' life expectancy increases, this becomes a key element of survival in later life. If the pump function in the heart is severely reduced there can be a range of symptoms including fast / slow rhythms and severe fibrillation. This can result in unheralded collapse and is the most common cause of death following myocardial infarction. However, outwardly similar collapse can be caused by heart stoppage / complete AV heart block and, in patients with advanced heart failure, clots can develop due to poor blood flow resulting in pulmonary embolism. The thing to note is that many of these outcomes would be outwardly indistinguishable and death can occur when a patient has been previously apparently stable. The study has now completed successfully, however we are waiting for an additional dataset on the cardiac scarring, as the data collection and analysis continues. The study also confirmed that arrhythmias occur in almost all patients with advanced cardiac dystophinopathy. Both atrial and ventricular arrhythmias were documented, and event longer episodes were asymptomatic or minimally symptomatic. Some patients were shown to have an increasing arrhythmia burden over time. Prolonged, comprehensive surveillance, made possible but he use of implemented devices, allowed the nature and frequency of arrhythmias to be documented and characterised. Preserving heart function and slowing the rate of myocardial scarring for as long as possible by prescribing medications from an early age are critical. A publication is being prepared. In addition, the findings from the study will be used to inform the discussion about the needs for a randomised controlled study of specific on device therapy to evaluate the risk-benefit of device therapy.
- **We supported a research project to study an alternative gene therapy delivery method with EVOX Therapeutics. The collaboration with EVOX on exosomes has been completed early. We have successfully demonstrated mRNA loading but optimising this process requires further work by EVOX alone.** In September 2018, we co-funded this project alongside Duchenne UK to investigate using exosomes, a potential alternative to using viruses, to deliver gene therapy. Exosomes are nanoparticles that all cells release, and which contain proteins and other large molecules. They are the body's natural way of effectively, safely, and repeatedly delivering molecules from cell to cell, and even crossing the blood brain barrier to access the brain. The aim of this project was to see if exosomes could be used to deliver gene therapy to muscle

cells. Several companies are now testing gene therapy in Duchenne, by using viruses to deliver the micro-dystrophin. However, many people with Duchenne may have pre-existing antibodies to the viruses being used to deliver gene therapy, which makes them ineligible for this treatment. Similarly, patients receiving viral gene therapy would develop immunity making repeated dosing, if required, impossible. We collaborated with EVOX – to look at ways of making gene therapy available to all patients. During this collaboration, EVOX has been able to load mini- and micro-dystrophin mRNA into exosomes (for technical reasons full-length dystrophin was not available for testing). EVOX has decided to carry out further optimisation of its mRNA loading approach work itself (and at its own cost) before then directing it towards the treatment of a variety of muscular skeletal diseases, including potentially Duchenne. Consequently, this work has been completed early.

- **We supported a Testosterone Extension Study to address delay in puberty due to steroid use in Duchenne and improving wellbeing in teenagers** – steroids are part of the recognised standard of care in treating Duchenne, but long-term use of steroids causes several side effects including delayed puberty. Testosterone is sometimes given to make boys begin going through puberty. It may also have other benefits. As the life expectancy of Duchenne patients' increases more young men are looking to establish relationships and lead independent adult lives. We are funding this research to ensure boys are given the correct hormonal treatment to allow them to develop properly. Our funds supported the clinical trial at the John Walton Muscular Dystrophy Research Centre (JWMDRC), led by Prof Volker Straub and Dr Claire Wood, treating 15 adolescents with Duchenne with testosterone to induce puberty. As well as looking at the effect of testosterone on pubertal development, growth, muscle strength and function, bone mineral density and body composition, the trial looked at the mood, quality of life and well-being of patients to assess their satisfaction with the benefits of the treatment compared to the side effects. This study has now successfully completed, and Prof Straub submitted a final report in October 2022. This work has highlighted; 1) the variation in endogenous testosterone after pubertal induction and the need for regular monitoring of testosterone levels in post-pubertal adolescents and adults with Duchenne. Prof Straub plans to propose ongoing monitoring of testosterone levels is included in the next revision of the DMD UK Standards of Care document; 2) increase in fat fraction after the cessation of exogenous testosterone, so a possible next step, could ne to consider whether an agent, similar in its properties to testosterone, would be beneficial in improving contractile muscle properties in Duchenne. This could potentially either be used pre-puberty, or once pubertal induction has been achieved. Finally, as a direct result from this work, Prof Straub is engaging with young men from the Pathfinders Alliance to seek their ideas, concerns and expectations regarding sexual health and fertility in Duchenne. If fertility is on the radar of some of these young men, then it will be important to consider ways to achieve optimal testosterone concentrations whilst maximising fertility prospects.
- **We supported a cancer drug showing promise as a treatment for Duchenne (TAM-DMD) – Tamoxifen, a drug to treat breast cancer, could be an effective treatment for Duchenne**. Using medicines already approved for other conditions to treat Duchenne is a key focus on what we fund. It's known as drug-repurposing and is attractive because it means potential medicines can be tested in clinical trials in far shorter timeframes. Tamoxifen is a cheap and readily available medicine, with a good safety record in adults. After receiving preliminary data from the trial in September '21, it was concluded that the trial did not show evidence for Tamoxifen effectiveness as a Duchenne treatment. This trial took place over 48 weeks. Whilst this trial did not provide the desired results, it has nonetheless provided learnings to help inform future Duchenne research.

- **We supported the The SOLID Suit (now known as The Smart Suit)** harnessing military technology to create wearable support for Duchenne patients. We're working hard to develop drugs to end Duchenne. But we're also trying to support people living with the condition. This soft, wearable, assistive device for patients, aims to help them perform day to day activities more easily. It uses cutting-edge military technology to power soft exoskeletons to support muscles. Since our investment, we are pleased to say that Duchenne UK has now signed a licensing agreement to make use of a patented twisted string actuator technology in The Smart Suit. Alex's Wish has continued to support this project and in January 2023, Alex Hallam trialled out the new prototype technology, and we can see how this suit will help support boys arm function in the future.
- **We provided financial support for three clinical posts to increase clinical trial capacity in the UK** - through the DMD Hub, helping ensure all patients in the UK with Duchenne, both children and adults, have access to clinical trials. A clinical trial is often a family's only hope of accessing potential new treatments that might one day become approved medicines. When Duchenne UK learnt that clinical trials were being turned away from UK hospitals, because of lack of doctors, nurses, and physiotherapists to run them, they alongside patient led charities like Alex's Wish collaborated to change this and the DMD Hub was formed. The Hub has already helped increase the number of UK sites which run Duchenne trials. We are extremely passionate about this project as it increases the opportunity for boys with Duchenne to get onto a clinical trial should they wish too.
- **We have provided financial support to The DMD Hub Manager for the next 4 years -** The DMD Hub is a collaboration between Duchenne UK, the John Walton Muscular Dystrophy Research Centre (JWMDRC) in Newcastle, and Great Ormond Street Hospital London. It was set up to expand clinical trial capacity and expertise and stop clinical trials being turned away from the UK. The DMD Hub has funded 30 posts, which ranges from research nurses to physiotherapists, from clinical research fellows to trial coordinators. The project team also developed the Clinical Trial Finder to help patients access information on DMD clinical trials in the UK. The tool includes information on each trial taking place, including selection criteria, age range, a lay summary and details of the sites that are recruiting. It was cited as an excellent example of digital infrastructure in a recent report by the Association of Medical Research Charities. Thanks to the DMD Hub, to date, more than 300 boys have been recruited to clinical trials who otherwise may not have been. Additionally, 11 UK hospitals are conducting 10 trials into potential treatments for DMD. Emma Heslop is the DMD Hub Manager and is key to the success of this project. Working closely with the Duchenne UK team, she ensures patients are appropriately represented as key stakeholders in all aspects of the DMD Hub. As part of the team at the JWMDRC in Newcastle, she has direct access to clinicians and industry partners through the relationships she has cultivated over the years. As the main point of contact for all companies with trials coming to the UK, she also promotes the UK as an attractive place to run DMD trials and works with them to support site selection, set up and patient recruitment. Her role also involves coordinating the staff networks for clinical trial coordinators, nurses, and lead clinicians, which include staff from across all eleven DMD Hub sites. These networks promote communication between the different sites so that they can share best practice and expertise. They also highlight any training needs, which the DMD Hub can then help to deliver. Her workplan for the next 4 years includes several exciting projects, which will have a significant impact for the DMD community: 1. Developing an operating procedure, adopted by all UK DMD Hub sites, to centrally coordinate patient recruitment to DMD trials 2. Conducting a Patient Preference survey, in collaboration with PPMD, to better understand patients and care givers perceptions of the benefits and risks of taking part in gene therapy trials 3. Conducting an Institutional Readiness survey to assess which hospitals in the UK can run gene therapy trials, and then to deliver a gene therapy licenced

product. The survey will also identify barriers to hospitals hosting trials, which the DMD Hub will work to address. 4. Facilitating the implementation of the DMD Care UK Project across all DMD Hub sites 5. Engaging with key initiatives in the UK facilitating gene therapy such as the Cell and Gene Therapy CATAPULT and the NA-ATTC (Northern Alliance for Advanced Therapies Treatment Centre) 6. Working with the MHRA (Medicines and Healthcare products Regulatory Agency) to ensure that post-Brexit, the UK remains an attractive site for trials.

- **We provided financial support to the Vamorolone project, a steroid-alternative drug** – Vamorolone is a steroid that has fewer side effects that traditional steriods. Since our initial investment to support the project, Santhera Pharmaceuticals and ReveraGen BioPharma has announced their new drug application (NDA) has been accepted by the US Food and Drug Administration (FDA) for review. In a recent update, Santhera announced they have applied to regulators in different countries for market authorisation, including the EU and the UK. At the same time NICE, the regulator responsible for assessing the clinical and cost-effective ness of drugs I England, announced a health technology assessment (HTA) for Vamorolone. HTA's assess whether a new treatment is clinically effective and cost effective for NHS patients. This is an exciting development, as NICE start the HTA process before marketing authorisation is granted, with an aim to have finished evaluating a drug soon after market authorisation is achieved. We continue to work with Santhera and the UK's regulators so Vamorolone can be rigorously evaluated and, if it's deemed suitable, made available to people with DMD in the UK.
- **We gave a grant to the Heartlands Hospital Charity in Birmingham** to help facilitate better access for children to the research trials. The money helped them purchase a large double plinth and a padded floor mat for the children to lie on for the therapy assessments. They also provided a manual wheelchair which means that they can transport ambulant children between the therapy department and the research centre. These pieces of equipment have been extremely useful and helped them to optimise their assessments and management of the children and young people with Duchenne. The funding also helped them to fund research time for a consultant doctor to increase the centre's ability to conduct clinical trials which has been invaluable to their service.
- **In addition, we have won seven prestigious awards in the East Midlands region and have been a finalist in a prestigious national charity award.**

Strategic Approach and Future Plans

Our strategy is to attract as much funding as possible, through the following core activities:

- Increase our level of income each year by building relationships with our existing supporters as well as attracting new supporters to our cause.
- Attract new businesses to our cause to ensure we have a pipeline of income scheduled for at least 12 months ahead.
- Develop new and existing fundraising streams and activities, with a view to increasing regular giving to help with the peaks and troughs of fundraising events streams. Through our ethical business club membership and our 'Be More Alex' regular giving campaigns.
- Concentrate on our core events calendar, whilst introducing new events that attract interest from different audiences such as our Supercars Day, and Grand Prix Challenge.
- Attract businesses who can donate a percentage of their income/sales revenue, Netmetix is a great example of this.
- Increase the number of touchpoints with new and existing supporters to demonstrate the impact made to our beneficiaries and to outline our future goals and fundraising initiatives. This includes our Spring launch and Annual Lunch inviting our supporters along to update them on progress and our future plans. We

also arrange 1-2-1 meetings and networking events with our business supporters to keep in touch and update them on our progress.
- Develop our relationships with the Trusts and Foundations who have supported so far, and to research new Trusts and Foundations to apply for funding.
- Recruit more ambassadors to our cause, to help spread the word about our cause and attract new supporters.
- Find opportunities to our Founder to speak at events to raise the profile of Alex's Wish.
- Continue to review operating costs and resources ensuring it is in line with our objectives.
- Continue to fund projects that will bring about effective treatments for Duchenne and aim to invest a £150,000+ per annum.
- Raise awareness and increase our visibility across the East Midlands region.

In the coming year we plan to:

Objective 1: To identify, fund and monitor medical research projects, clinical trials, clinical trial capacity opportunities and new technological advances.

- To receive updates on outcomes for all projects funded so we can report on the impact those projects have made to help progress our mission. To report on these via our news feeds on our website, social media, e-newsletters to our supporters and through local press coverage.
- Continue to work closely with Duchenne UK as a Charity Partner, to seek out and fund new and exciting clinical trials, medical research projects, clinical trial capacity opportunities and new technologies as and when it arises ensuring that our funds are spent effectively and in the right areas to help bring about the best chances of bringing new treatments to market.

Objective 2: To continue lobbying government and other regulators and to engage with media and our supporters to raise awareness of Duchenne Muscular Dystrophy

- Attend national events and meetings to help lobby MPs and Parliament to bring about new treatments to market as quickly as possible e.g. Vamorolone and Givinostat.
- Attend Duchenne Parent Days run by Duchenne UK and the National Action Duchenne Conference to engage with other parents affected by Duchenne Muscular Dystrophy, as well as keep abreast of latest progress made in the field of Duchenne.
- Continue to write press releases and submit to the local press in the East Midlands to help raise awareness about the work we are doing and its impact on the local community / the rest of the UK and to help attract new supporters to our cause.
- Continue to send regular updates to our supporters via e-newsletters, website and social media and keep interest and support our ongoing work.
- To organise Supporter events such as our annual Spring and Autumn Thank You events to keep in touch with our supporters about the vital work that we do.
- Continue to attend networking events within the region to build new and foster existing relationships and attract new supporters to our cause.

Objective 3: Fundraise through our flagship events, supporter events and fundraising activities:

- Organise flagship events: Golf Day, Supercars event, Football Tournament, Annual Fundraising Ball and support other organisations and individuals organising events in support of our goals.

- To attract supporters to take part in the Prudential Ride London, London Marathon, Sky Dives, Quiz Nights, family-fun walking and running events, challenge events e.g., Zipwire challenges, Sky Dives, Loop the Loop, and Abseil Challenges.
- We aim to work within a 30:70 ratio of cost of an event to income received from an event to ensure that 70% of what we raise from our events overall goes directly to potential life-saving treatments. We would like to attract more capital through corporate sponsors to cover off most of our event costs to help bring this ratio down as low as possible. We have been successful in attracting corporate sponsors and will continue to build those relationships.
- Majority of our income raised has been through hosting our own events. Our aim is to continue working with local businesses to take Alex's Wish on as their chosen charity and organise their own events and consider Alex's Wish as their Charity of the Year. This means that 90%+ of the money they give to us as a Charity goes directly to life-saving treatments as they do not incur the expenditure that our own fundraising activities require.
- Continue to work closely with Miss Great Britain who has chosen Alex's Wish as one of their two charities to support 2020-2023 and will work closely with them to help with their personal fundraising initiatives.
- Continue to promote our 'Be More Alex' campaign designed to attract regular givers to give £7 per month to our cause.
- Continue to grow our 'Ethical Business Club' who give £75 per month, by attracting local organisations to support our cause through a regular donation in exchange for business benefits such as organising local networking events to bring the local business community together. Continue to retain our Club Sponsors, Janine Edwards Wealth Management and Spirit Healthcare.
- Continue to work with The Brothers Trust foundation, St. James Place Charitable Foundation and With Love, Steph foundation and other local charitable groups.
- Form strategic alliances and partnerships with organisations such as local sporting clubs, colleges, schools, and corporate businesses.
- Continue to attend local networking groups throughout Leicestershire and the East Midlands with the primary aim of building relationships and raising awareness of Duchenne amongst the local business community.

Structure, Government and Management

The organisation is a charitable company limited by guarantee, incorporated on 22 June 2012. The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £10.

The body responsible for management of the Charity is the Board of Trustees of Alex's Wish. The Board meets monthly (and at least ten times per year). The charity's constitution is set out in the Articles of Association, and all Trustees have agreed to this. New Trustees are appointed by the existing Board of Trustees. Trustees give of their time freely and no Trustee remuneration was paid in this year. Details of Trustee expenses and related party transactions are disclosed in the accounts. Trustees are required to disclose all relevant interests and to withdraw from decisions where a conflict of interest arises. None of the Trustees have any interests with the pharmaceutical industry.

We regularly review our stated aims, objectives, and activities to ensure we are working toward our stated purposes. We have referred to the guidance contained in the Charity Commission's general guidance on public benefit under the Charities Act 2011 when setting and reviewing our aims and objectives and in planning our future activities. All our charitable activities focus on improving the lives of those with Duchenne Muscular Dystrophy and research into the disease.

Trustee Recruitment

Trustees will be recruited through advertising in local newspapers, and through social media, at our events and through word of mouth. Those expressing an interest will, in the

first instance, be met by the Charity Founder, given an overview of the organisation, and encouraged to apply. The Chair and another trustee will examine the applications against the most recent skills audit, produce a short list, and invite those on it to submit their references and then attend an interview; the Chair and another trustee will conduct the interviews, and make recommendations to the Board. At its next meeting, the Board will review these recommendations, and either ratify or reject. Successful applicants will be asked to complete and sign the declaration of interest form, sign a declaration that they are eligible to serve as a trustee; and agree to the code of conduct. They will then become a trustee of the Board.

Risk Management
The Trustees continue to review the major strategic, business, and operational risks which the charity faces and confirm that systems are in place to enable regular reports to be produced so that the necessary steps can be taken to lessen these risks. In assessing risk, the Trustees recognise that some areas of the work require the acceptance and management of risk if the charity is to achieve its objectives.

Basis of Preparation of Accounts
The accounts have been prepared in accordance with the accounting policies set out in note 1 of the accounts and comply with the charity's governing document, the Companies Act 2006 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) (as amended for accounting periods commencing from 1 January 2016).

Financial Reserves Policy
The Charities SORP requires a charity to state the amount and type of financial reserves it holds, and to compare how the level of those reserves matches up to "The level of reserves the trustees feel as appropriate given their plans for the future activities of the charity". Where it falls short, the trustees need to explain what steps they are taking to rectify the situation. In this context, the charity views financial reserves as those held in its unrestricted funds, the balance of funds stood at £142,076 at the year-end (2021 £140,163). The Trustees establish the appropriate level of unrestricted reserves (over and above those already ring-fenced for plans or known liabilities within restricted and designated Funds) by seeking to ensure that the level of the charity's 'free reserves' meets a chosen benchmark related to the budgeted expenditure for unrestricted activities. The Trustees consider the "free reserves" to be the unrestricted funds not committed or invested in tangible assets. As a result of a full and objective review of its 'free reserves' policy, considering all the risks foreseeable at that point and the charity's approach to their mitigation, the Trustees agreed on 9th February 2023 that £30,000 should be maintained as 'free reserves'. This level has continued to be reviewed for adequacy and robustness to ensure the Charity maintains adequate finances to meet day-to-day operating costs, and we will continue to review this over the coming months. As of 30 June 2022, the Charity's "free reserves" stood at £142,076 (2021: £140,163), resulting in a surplus of £112,076 (2021: surplus of £120,163) when compared with the current benchmark, calculated as £30,000.

Statement of Trustees' Responsibilities
The Trustees (who are also Directors of Alex's Wish for the purposes of company law) are responsible for preparing the Trustees' report and the accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare accounts 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 accounts, the trustees are required to:

- Select suitable accounting policies and then apply them consistently;

- Observe the methods and principles in the Charities SORP;
- Make judgements and accounting estimates that are reasonable and prudent;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- Prepare the accounts on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the accounts 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.

This report was approved by the Trustees on 23rd March 2023 and signed on their behalf by



Mrs EJ Hallam

Independent Examiner's Report to the Trustees of the Alex's Wish

I report to the charity Trustees on my examination of the accounts of Alex's Wish for the year ending 30 June 2022, which are set out on pages 19 to 23.

Responsibilities and basis of report

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

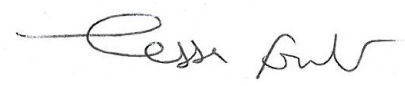
Having satisfied myself that the accounts of the charity are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act').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

Independent examiner's statement

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

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)

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



23rd March 2023

TD Fowler BA FCA
Chartered Accountant for
HSP Tax & Accounts Ltd
Whiteacres
Cambridge Road
Whetstone
Leicestershire
LE8 6ZG

Statement of Financial Activities

For the year ended 30 June 2022

	Note	Unrestricted funds 2022	Total 2021
		£	£
Income from:			
Donations		**16,843**	28,979
Fund-raising activities		**206,169**	100,799
Bank interest received		**59**	10
Grants received		**2,809**	24,360
Total income		**225,880**	**154,148**
Expenditure on:			
Charitable activities	2	**(223,967)**	(122,645)
Net income for the year/net movements in funds		**1,913**	31,503
Fund balances at 1 July 2021		**140,163**	108,660
Fund balances at 30 June 2022		**142,076**	140,163

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

Balance sheet

At 30 June 2022

	Notes	**2022 £**	**2022 £**	2021 £	2021 £
Current assets					
Debtors	*3*	**12,925**		17,222	
Cash at bank and in hand		**138,717**		134,898	
		151,642		152,120	
Creditors:					
Amounts falling due within one year	*4*	**(9,566)**		(11,957)	
Net current assets			**142,076**		140,163
Total assets less current liabilities			**142,076**		140,163
Funds					
Unrestricted funds	*5*		**142,076**		140,163
Restricted funds	*5*		**-**		-
Total Funds			**142,076**		140,163

For the year ending 30 June 2022 the charitable company was entitled to exemption from audit under Section 477 of the Companies Act 2006.

The Trustees acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply with section 386 of the Companies Act 2006 and for preparing accounts which give a true and fair view of the state of affairs of the charitable company as at the end of the financial year and of its incoming resources and application of resources, including its income and expenditure, for the financial year in accordance with sections 394 and 395, and which otherwise comply with the requirements of the Companies Act 2006 relating to accounts, so far as applicable to the charitable company.

The members have not required the charitable company to obtain an audit of the accounts for the year in question in accordance with section 476.

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

These financial statements were approved by the Trustees on 23rd March 2023 and were signed on their behalf:



Mrs EJ Hallam
Trustee and Director

Notes

(forming part of the unaudited financial statements)

1 Accounting policies

Company status

Alex's Wish is a private company limited by guarantee. The registered office is The Old Vicarage, High Street, Syston, Leicestershire, LE7 1GP. The members of the company are the Trustees as detailed in the Legal and Administration information who are also the Directors of the company for company law purposes. In the event of the charity being wound up the liability in respect of the guarantee is limited to £10 per member of the charity.

Accounting convention

The accounts have been prepared in accordance with the charity's governing document, the Companies Act 2006 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) (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP the charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

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

These accounts have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

Going Concern

The financial statements have been prepared on a going concern basis. Having carried out a detailed review of the Charity's resources and the challenges presented by the current economic climate, the Trustees are satisfied that the Charity has sufficient cash flows to meet its liabilities as they fall due for at least one year from the date of the approval of the financial statements. The Trustees do not consider there to be any material uncertainties and continue to adopt the going concern basis in preparing the financial statements as outlined in the Trustees' Responsibilities Statement. There are no significant financial uncertainties that the Trustees consider are a significant risk to the ability of the Charity to trade as a going concern in the foreseeable future.

Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used.

Incoming Resources

All income is recognised when the charity has entitlement to the funds, it is probable that the income will be received, and the amount can be measured reliably.

Incoming resources relating to specific events are recognised in the accounting period in which the event takes place.

Resources Expended

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Support costs are those costs incurred directly in support of expenditure on the objects of the charity and include project management carried out.

Costs relating to specific events are recognised in the accounting period in which the event takes place.

There were no employees whose annual renumeration was more than £60,000.

Financial instruments
The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transactional value and subsequently measured at their settlement value.

Taxation
The charity is exempt from corporation tax on its charitable activities.

Grants
Grants are credited to deferred revenue. Grants towards capital expenditure are released to the profit and loss account over the expected useful life of the assets. Grants towards revenue expenditure are released to the profit and loss account as the related expenditure is incurred.

2 Charitable Activities

	2022	2021
	£	£
Payments for medical research, clinical posts and new technologies	**117,000**	62,142
Expenditure on charitable events	**41,305**	7,666
Administrative services	**51,761**	45,386
Other expenses	**13,901**	7,451
	223,967	122,645

3 Debtors

	2022	2021
	£	£
Amounts owed for event income	**-**	244
Trade debtors	**729**	280
Prepaid event costs	**12,196**	16,698
	12,925	17,222

Notes - continued

(forming part of the unaudited financial statements)

4 Creditors: amounts falling due within one year

	2022	2021
	£	£
Income received in advance of events	**9,566**	11,957

5 Movement in Funds

	At 30 June 2021	Net movement in funds	**At 30 June 2022**
	£	£	**£**
Unrestricted funds	140,163	1,913	**142,076**
Restricted funds	-	-	**-**
Total Funds	140,163	1913	**142,076**

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds	225,880	(223,967)	1,913
Restricted funds	-	-	-
Total Funds	**225,880**	**(222,649)**	**1,913**

6 Employees:

	2022	2021
Average number of employees during the year	**2**	2

Employment costs:

	2022	2021
	£	£
Wages and salaries	**50,284**	43,873
Pension costs	**1,477**	1,316
	51,761	45,189

Detailed Statement of Financial Activities

for the year ended 30 June 2022

	2022 £	2022 £	2021 £	2021 £
INCOMING RESOURCES				
Incoming resources from charitable activities				
Donations		**16,843**		28,979
Fund-raising activities		**206,169**		100,799
Total incoming resources		**223,012**		129,778
RESOURCES EXPENDED				
Charitable activities				
Charitable event expenditure:				
			16	
Big Christmas Give Campaign	**-**		4	
Annual Golf Day	**5,437**		-	
Coast to Coast Cycle Ride	**-**		1,419	
Tour de Alex (Virtual)	**-**		72	
Prudential Ride London	**4,482**		560	
Annual Fundraising Ball	**15,829**		-	
Masquerade Ball (Virtual)	**473**		3,169	
			33	
Ethical Business Club	**165**		5	
London Marathon	**700**		-	
The Brothers Trust	**-**		324	
Supercars Charity Event	**761**		270	
Charnwood Forest Cycle Ride	**1,015**		-	
'Be More Alex' regular giving campaign	**869**		632	
Abseil Charity Event	**2,475**		-	
AGM/Annual Supporters Thank You Lunch	**4,107**		649	
Miss Great Britain Finals Event	**524**		-	
Skydiving Events	**900**		-	
6 A Side Charity Football Event	**1,267**		-	
Tabletop Sale	**150**		-	
Loop the Loop Challenge with AeroSparx	**1,938**		-	
Stan Hulme's Nordic Challenge	**175**		-	
Other sundry event costs	**38**		72	
		(41,305)		(7,666)
Net proceeds from charitable activities		**181,707**		122,112
Overheads				
Administrative Services:				
Event Management	**36,233**		31,770	
Administration	**15,528**		13,616	
Business Development & Networking Events	**6,204**		3,780	
Promotional Materials	**992**		424	
Website & Email Marketing	**360**		38	
Bookkeeping and Legal Fees	**237**		223	
Travel and Subsistence Expenses	**1,436**		-	
Insurance	**445**		445	
Bank charges	**361**		185	
Training	**159**		-	
Printing, Postage and Stationery	**7**		-	
Computer and Software Costs	**3,700**		2,356	

	(65,662)	(52,837)
Bank interest received - gross	**59**	10
		69,285
	116,104	
Payments for Medical Research, Clinical Posts and New Technologies.	**(117,000)**	(62,142)
Government grants received	**2,809**	24,360
Net incoming resources	**1,913**	31,503

This page does not form part of the unaudited accounts.

ALEX'S WISH

England & Wales - Charity number 1148845

Accounts

ALEX's WISH
cure Duchenne

Alex's Wish

Company Limited by Guarantee

Trustees report and unaudited financial statements

Registered company number 08116159

Registered charity number 1148845

30 June 2021

ALEX's WISH
cure Duchenne

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Legal and administration information

Trustees & directors	Mr AR Hallam Mrs EJ Hallam Mr S Dean Mr CR Everard Ms R Hargrave Mrs J Edwards Ms G Wright Ms S Barnett Ms AL Slack Mr S Jesrani Mrs K Boorman Mr TW Carter
Company No	08116159
Charity No	1148845
Website:	www.alexswish.org
Registered office	20 Granite Way Mountsorrel Leicestershire LE12 7TZ
Independent Examiner	HSP Tax & Accounts Ltd Whiteacres Cambridge Road Whetstone Leicestershire LE8 6ZG
Bankers	National Westminster Bank plc

Trustees' report

The Trustees present their report and unaudited financial statements for the year ended 30 June 2021.
The Trustees, who are also Directors of the charitable company for the purposes of the Companies Act, and who served during the year and up to the date of signature of the financial statements were:

- Emma Hallam, Founder and Chief Executive Officer
- Andy Hallam, Founding Trustee
- Stephen Dean, Chair and Trustee
- Chris Everard, Trustee
- Rachel Hargrave, Trustee
- Janine Edwards, Trustee
- Glynis Wright, Trustee
- Sally Barnett, Trustee
- Alexandra Slack, Trustee
- Sandesh Jesrani, Treasurer
- Kelly Boorman, Trustee (Appointed 14 January 2021)
- Thomas Carter, Trustee (Appointed 20 June 2021)

The Trustees confirm that the annual report and financial statements of the charitable company comply with the current statutory requirements and the provisions of the Statement of Recommended Practice (SORP) Accounting and Reporting by Charities.

Registered Office: 20 Granite Way, Mountsorrel, Leicestershire, LE12 7TZ

Website: www.alexswish.org

Registered Charity No: 1148845

Scientific Advisory Board. We work closely with Duchenne UK as their Charity Partner and as such most projects that we fund are co-funded alongside them. All projects put forward to us for potential funding go through their rigorous Scientific Advisory Board, which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy. It includes the different skills of doctors, scientists, and drug developers so that each project is asked the right questions: Is this good science? Can this be taken into clinic? What hurdles exist? Is this replicated anywhere else? Duchenne UK's advisory board consists of:

- Professor Dame Kay Davies
- Dr Eric Hoffman
- Professor Annemieke Aartsma-Rus
- Dr. John Bourke
- Professor Dirk Fischer
- Dr. Dada Pisconti
- Dr. Valerie Riccoti
- Frank Robertson
- Dr. Olivier M Dorchies
- Dr Manuela Corti

Professional Service Providers
Independent Examiner:
Tessa Fowler BA FCA
HSP Tax & Accounts Ltd
Whiteacres, Cambridge Road
Whetstone
Leicester LE8 6ZG

Bankers
National Westminster Bank plc
5 The Parade, Oadby, Leicester LE2 5NT

Alex's Wish would like to thank its Trustees, service providers, scientific advisors, and supporters for kindly giving their time and expertise to grow the charity.

Statement from the CEO and Charity Founder, Emma Hallam

It's almost 10 years since we launched Alex's Wish in late 2012 after our son, Alex, was diagnosed with Duchenne Muscular Dystrophy. When the diagnosis was confirmed, we were absolutely devastated as doctors told us there was NO CURE and NO TREATMENTS available other than steroids which cause serious side-effects and, at best, would help delay the onset of his condition by two years at most.

Duchenne is a life-changer. It affects every single day of your life as you must be prepared for ever-changing challenges that affect your child's day to day activities. Duchenne is a progressive, muscle wasting disease. It is relentless affecting every single muscle in the body. One day your child may not be able to walk, may not be able to lift a cup to their mouth, may not be able to play round at their friends' houses anymore. We felt overwhelmed and terrified of what the future held for our son, living in fear of the next stage of progression and wondered how we would cope.

At the time of diagnosis, we quickly realised we have no time to waste. We investigated the latest scientific research and understood that without ongoing funding this work would not continue. We set-up Alex's Wish, a local charity based in the heart of Leicestershire, as we knew we would attract interest and support from local supporters and businesses across the East Midlands and bring in additional funds to what was already being raised. We do not duplicate the efforts of other charities working in this field instead our focus is to **drive additional funds** allowing us to co-fund scientific projects with other charities like Duchenne UK who are also working to end Duchenne.

The science is at a very exciting time; a time of hope of new treatments being just around the corner. We've seen the first Duchenne patient being dosed in a gene therapy trial in the UK. The research that we have funded is bearing fruit with a successful Phase 2 trial results of Vamorolone, a steroid alternative. We are very hopeful that one day a cure to end Duchenne will become available.

We are delighted with our progress to date and excited about the times ahead. We are incredibly grateful to our wonderful supporters who have come on this journey with us so far.

We would like to say a **very special thank you** to the following people and organisations

- Duchenne UK, a charity run by two mums who also have sons living with Duchenne, for the incredible work they do and by collaborating with them, we ensure we only ever invest in the best science available.
- Our fundraising and support team Zoe Edwards and Heidi Eastell for their enthusiasm, hard work and dedicated support. They contribute significantly to the day-to-day running of the Charity and its success.
- To the following businesses who donate their services in kind: HSP Tax for producing our annual accounts and reporting, Brand Clear creative agency for offering their creative services, Flexpress for print and production, New English Design for website hosting, Winstanley House for hosting our Ethical Business Club events at their venues, Delta Global for our promotional bags, Fashion UK for our branded t-shirts and to Brooksure Insurance for our annual insurance and those suppliers who work with us on a day-to-day basis providing services at a reduced costs. And to Hallam Read who give us office space at zero cost to keep our running costs low.
- Our dedicated Trustees for their continued support, help in running the charity, providing a great platform to discuss future goals and initiatives, much-valued feedback and for their introductions to new supporters. Despite the Pandemic they have remained resilient and with us have helped make vital decisions to ensure our charity is sustainable in the longer-term.

- Every single business, club and supporter who has either chosen us as their Charity of the Year, sponsored our events, organised events for us, attended our flagship events and taken part in various challenges, donated items and experiences for our fundraising auctions and raffles, our ethical business club members and to our ambassadors who shout from the rooftops about the work we do. There are too many to list individually, however we list all businesses who support our cause on our website, and feature supporter stories across our social media sites and through our news stories which are also released to the local media.
- To our major donors for their financial contributions during period, including The Brothers Trust, Leicestershire Law Society, Netmetix, Miss GB, and Janine Edwards Wealth Management.

In this financial year, we have invested £62,142 (£75,000 in 2019-2020) in three projects:

- Project 1 - A post held at Newcastle University, Dr Michela Guglieri, the fifth and final year - £7,142
- Project 2 - Phase 2 Study of Edasalonexent in older boys (non-ambulant population) - £30,000
- Project 3 - Research Study – Lipid Nanoparticles - £25,000

Shortly after investing in the Edasalonexent study with Duchenne UK, we were informed that this study would be terminated. In addition, a project we had previously invested with Duchenne UK back in 2019, The EVOX Study was completed early with £43K of monies raised by Alex's Wish being unspent. After consultation with Duchenne UK, we took the decision that these un-spent funds (£73K in total) be retained at Duchenne UK and re-ringfenced for new projects. Alex's Wish would retain the right to make decisions as to where these funds would be re-allocated. During this accountancy period, with consultation with our Trustees Board, all funds were re-allocated into the following projects, full details of which are given later in this report:

- Project 3 - Research project – Lipid Nanoparticles - £5,000 (this is the same project as above)
- Project 4 - Research project – To address the lack of accessible housing - £3,000
- Project 5 - Research project – To improve the knowledge of heart care in Duchenne patients - £10,000
- Project 6 - Diagnosing cardiac fibrosis in female carriers of Duchenne - £15,000
- Project 7 - Increase Clinical Trial Capacity: DMD Hub Manager post for 4 years - £40,000

As the Pandemic continues, our Board of Trustees rightly took the decision to take a cautious approach to funding to ensure our financial sustainability in future years. It is important that our work helps support both this generation and future generations affected by Duchenne. As at writing this report, February 2022, we can report that we have £208,000 funds held in our savings account and most of these funds will be pledged shortly into **five** exciting projects proposed by Duchenne UK to further our mission.

Our revised target for our next financial year, is to raise £200,000 (1st July 2021 - 30th June 2022) and, at the time of writing this report, we stand in good stead to achieving this, as £173,196 has already been raised towards this target. This is despite the Pandemic causing major disruption to our fundraising activities and events and we are incredibly proud of what we've still been able to achieve.

We are incredibly positive about the future and Alex's Wish gives us hope. Duchenne Muscular Dystrophy is part of our lives, not out of choice, but we will make it as best as we can, and we will never stop our journey to conquering Duchenne.

We could not have done our work without the support of our army of supporters, the local business community, business sponsors, ambassadors and our dedicated trustees and we would like to express our gratitude and thanks to every single one of them.

Emma Hallam
Charity Founder

About Duchenne Muscular Dystrophy

Duchenne Muscular Dystrophy is a devastating life-shortening genetic disease that affects 1 in every 3,500 boys born (it also affects girls who account for 1% of all those diagnosed). It is caused by a mutation in the gene that encodes for dystrophin, a protein that is essential to the proper functioning of our muscles. Without dystrophin, muscles are not able to function or repair themselves properly. The loss of muscle then results in a loss of strength and function.

Duchenne can be passed from parent to child, or it can be the result of random spontaneous genetic mutations, which may occur during any pregnancy. In fact, about one out of every three cases occurs in families with no previous history of Duchenne. In other words, it can affect anyone, and crosses all races and cultures. The average age of a Duchenne diagnosis is around 4 years old. Many times, there will be delays in early developmental milestones such as sitting, walking, and/or talking. Speech delay and/or the inability to keep up with peers will often be the first signs of the disorder.

Duchenne progresses differently for every person. Even siblings with the same mutation may have a very different progression of symptoms. Muscle loss is first noticed in childhood, with loss of strength, function, and flexibility in the hips, thighs, shoulders, and pelvis. In teens these losses begin progressing to the arms, lower legs, and trunk. Because there is also an absence of dystrophin in the muscles of the heart and lungs, heart function and breathing are also affected. In addition, some people can have issues with learning and behaviour resulting from a lack of dystrophin in the brain.

The progression of symptoms through Duchenne are on a spectrum from late onset/very mild symptoms to early onset/severe symptoms. Regular visits with a neuromuscular team help to monitor the progression of disease and how it can best be treated along the way. With improved care more people with Duchenne are living into their 30s and beyond. With clinical care continuing to improve, as well as clinical trials, research, and therapies on the horizon, we are hoping to enhance the quality of life and extend the lives of those affected.

A carrier of Duchenne is a woman who has a mutation in one of her two copies of the dystrophin gene. Carriers have an increased chance of having sons with Duchenne and daughters who are carriers. Female carriers are usually not affected with Duchenne because they make enough of the dystrophin protein. However, they can have some symptoms of Duchenne such as muscle weakness and heart problems. Though it is rare, some females can have the classic symptoms of Duchenne.

Duchenne in numbers

- 1 of the most serious genetic diseases in children
- 1 in every 3,500 boys born will have Duchenne
- 2,500 boys affected in the UK
- 300,000 boys affected worldwide
- 2 families per week receive diagnosis in the UK
- 90% of boys will require the use of a wheelchair by the age of 12

What we are doing about it

We are committed to continuing to drive momentum to deliver treatments to help **THIS generation** of those with Duchenne. We have invested hundreds of thousands of pounds in both research and clinical trials as well as supporting hospitals to run trials, helping us move ever closer to effective treatments for Duchenne. We have an innovative approach to funding. Not only do we fund basic research, but we fund clinical trials and the doctors and nurses in the UK to deliver those trials.

Our Vision

Our Vision is a world without Duchenne Muscular Dystrophy. We want a future that stops the devastating impact Duchenne has on our children and young adults, a future where they can grow and prosper and fulfil their dreams; a life where they can enjoy every day without the fear of the progression this muscle wasting disease has on their bodies. A future without Duchenne would be a bright and happy future for all those affected. We need to act quickly to save this generation. Doing nothing is not an option. Our boys and their families need to live without fear and have hope for the future.

Our Mission

Alex's Wish was set-up by a family affected by Duchenne, who understand first-hand the impact this condition has on their child and the family. As a family we are taking part in clinical trials ourselves as we understand the importance of clinical trials and how they will help being effective treatments to market. We have one clear mission; to conquer Duchenne soon. We are doing this by funding medical research that's focussed on getting treatments to those affected now as well as pushing for effective treatments in the future. Our ultimate focus is to extend/improve the lives of those living with Duchenne, to halt or reverse the effects of muscle wasting.

Our Urgent Need for Funding

We need to provide substantial funding to several clinical trials and research projects over the next five years that will provide a catalyst to drive significant investment from biotech and pharmaceutical companies. A significant factor in getting treatments out of the laboratory and into clinic is funding! Rare diseases get very little funding from the Government due to the low levels of numbers affected by rare conditions.

Charities like ours fund half of all medical research in the UK – to the tune of £1.7 billion. Today, 1 in 4 people choose to support medical research charities like ours, and for this we are so incredibly grateful.

Impact of Coronavirus

During the period from 1 July 2020 to the date that these financial statements were approved, the coronavirus (COVID-19) outbreak has continued to spread worldwide and caused extensive disruptions to businesses as well as economic activities globally including the UK.

We have considered the effects of the 2020 outbreak of COVID-19 on the charity's operations and have concluded that the impact on it is likely to be limited. Following the advice issued by the UK Government in March 2020 regarding employees working from home and other social distancing measures, we have enacted procedures to facilitate this and have a detailed plan that enables effective operation to continue whilst employees are not physically present in the charity's offices. Trustees acknowledge and recognise the potential impact of the COVID-19 pandemic on the future operations of the charity, its beneficiaries, partners, and stakeholders and on wider society. As well as the personal risk to health of its staff, the charity may lose planned income as the result of the cancellation of events and/or the absence of key personnel. It is not anticipated at the current time that the overall financial position of the charity will be adversely affected, or its financial solvency threatened.

Our Progress

- Continued to increase funds raised each year and have continued to raise funds despite the impact of the Pandemic in 2020 and 2021.
  - Y1 - 1 July 2012 to 30 June 2013 - £53,025
  - Y2 – 1 July 2013 to 30 June 2014 - £83,962
  - Y3 – 1 July 2014 to 30 June 2015 - £134,263
  - Y4 – 1 July 2015 to 30 June 2016 - £124,885
  - Y5 – 1 July 2016 to 30 June 2017 - £157,626
  - Y6 – 1 July 2017 to 30 June 2018 - £197,688
  - Y7 – 1 July 2018 to 30 June 2019 - £218,518
  - Y8 – 1 July 2019 to 30 June 2020 - £201,178
  - Y9 – 1 July 2020 to 30 June 2021 - £129,778 (reduction in funds raised due to the Pandemic)

- Kept our operating costs within 41% of total funds raised £52,837; of which £13,616 (10% of total funds raised) was for administration to manage the day-to-day tasks, £31,770 (24% of total funds raised) was to manage our events and fundraising activities and £7,451 (6% of total funds raised) was spent on promotional materials, insurances, bank charges, marketing, bookkeeping, business development and networking events.

- As a Charity we have made use of the government's furlough scheme and placed our employees onto part-time furlough during the Pandemic which has enabled us to protect those jobs whilst giving them job

security and peace of mind. The reason we utilised this scheme is because as a Charity we rely on the income generated from our flagship events, and during the Pandemic our physical events have been cancelled due to government restrictions being in place. The safety of our supporters, employees and the wider community is paramount. It has allowed us to protect the income generated before the Pandemic hit and ensured that monies raised from supporters are used for the purposes of our mission to conquer Duchenne for all. The scheme has been a lifesaver and has helped keep costs low, whilst still ensuring we were able to continue to run virtual events and keep in touch with our supporters. The view of the Trustees is to ensure Alex's Wish is sustainable and will be able to function and carry on with our intended purpose for years to come.

- Prior to the Pandemic hitting, we continued to increase funding into innovative projects year on year and invested a total of £662,465 towards research, clinical trials, and increasing clinical trial capacity.
  - Y2: £28,415
  - Y3: £74,100
  - Y4: £73,661
  - Y5: £92,862
  - Y6: £112,143
  - Y7: £144,142
  - Y8: £75,000 (this is lower than forecasted due to the impact of the Pandemic)
  - Y9: £62,142 (this is lower than anticipated as we took a cautious approach to investing due to the impact of the Pandemic)
  - As at writing this report in March 2022, we have an additional £200K due to be invested imminently.

Our Charitable Objectives

1. The principal objects of the charitable company are the relief of sickness and the preservation of good health by supporting scientific research into the improved diagnosis, prevention, or treatment of Duchenne Muscular Dystrophy. This is to be achieved by:
   a) Extending the current scope of drugs / treatments so that they will help all children with Duchenne Muscular Dystrophy.
   b) Fund first stage clinical trials that provide the safety and efficacy of some of these treatments and then progress this into larger scale production.
   c) Fund the completion of scientific work already begun, to bring it to clinical trials, and fund other forms of treatment that will work on all children regardless of their genetic mutation.
   d) Fund studies that will help bring about data and information to help decision makers make decisions on which treatments to bring to market.
   e) Fund The Newcastle Plan – there is an increasing community wide focus on clinical trial capacity in the UK and Treat-NMD has co-ordinated and organised a national meeting in Newcastle concerning the apparent lack of capacity for trials in Duchenne. This brought together 75 stakeholders representing patient organisations, clinical experts, the pharmaceutical industry, as well as the National Institute for Health Research (NIHR), to develop a strategy to improve capacity and better utilise existing resources. All stakeholders contributed to shaping 'The Newcastle Plan' and concluded that the UK must maintain its place as one of the 'go to' countries for clinical trials in Duchenne, posting a five-year objective to ensure that all potential children and adults with Duchenne, have access to clinical trial research opportunities.

2. Advance the education of the general public, in all areas relating to Duchenne Muscular Dystrophy by disseminating information on the disease and its treatments and cures. To:
   a) Disseminate information using online and offline materials, including the charity's website www.alexswish.co.uk and our World's Strongest Boys video https://youtu.be/0uxxh3xk0_g
   b) Running events and fundraising activities and promoting our work on social media:
      Facebook **https://www.facebook.com/alexswishcharity1**
      Twitter **https://twitter.com/alexswish**
      You Tube **https://www.youtube.com/channel/UCU-RRlMhQmkhBhNyIsS6hZA**
      Linked In **https://www.linkedin.com/company/9202750/admin/**

Instagram https://www.instagram.com/alexs_wish/

c) We have built great relationships with the local media outlets in our region and regularly generate news articles and updates in local newspapers, including The Leicester Mercury and The Loughborough Echo and local magazines posted through doors. We also appear regularly on the local radio stations including BBC Radio Leicester to raise awareness about Duchenne and the impact this has on families living with it. We are working with RDZ-PR public relations agency to develop news-worthy stories.
d) Talking and presenting at various events on Corporate Social Responsibility, the impact of living with Duchenne Muscular Dystrophy, About Alex's Wish and Resilience – it is important our personal story is shared amongst others.
e) Participate in alliances and liaise with the Government to inform policy makers and other stakeholders about the work of the charity, the nature of the disease and potential treatments and cures.

Our Grant Making Policy and Collaboration

The Charity has established its grant making policy to achieve its objectives for the public benefit to find a cure for Duchenne Muscular Dystrophy and to slow down the rate of progression by maintaining muscle strength for longer leading to increase life expectancy as well as a better quality of life.

We only want to fund great science – projects that can improve the knowledge base and bring treatments that can reach the clinic and improve the lives of boys with Duchenne Muscular Dystrophy in many ways.

We formed a partnership with Duchenne UK. Duchenne UK share the same mission and objectives as Alex's Wish and are also a parent-led charity. As a Charity Partner to Duchenne UK, we receive projects that require co-funding. All such projects have been reviewed extensively by their Scientific Advisory Board which is made up of some of the world's leading experts in Duchenne Muscular Dystrophy. They bring with them a wide range of essential skills and knowledge basis including scientific, clinical and drug discovery and development. When scientists approach Duchenne UK with their ideas for new research projects it is the SAB who apply their experience and expertise to test these ideas, helping to refine them, if necessary, in order that Duchenne UK can make informed decisions on funding. Alex's Wish Trustees review all projects put forward before deciding upon specific projects to fund.

We also work with Solid Biosciences to help progress their Gene Therapy (SGT-001) programme and this work is now progressing into clinical trials and is showing great promise.

We have worked with Muscular Dystrophy UK to co-fund research and clinical trials. Alex's Wish is part of the Duchenne Forum, a partnership between six UK Duchenne-led charities to help accelerate progress in the search for effective treatments and eventually cures. The partnership is supporting seven pioneering Duchenne research projects committing to £840,000 over a four-year period.

We have worked with Action Duchenne and co-fund projects as such as the Repurposing Cancer Therapeutic drug called Dasatinib – a drug commonly used to treat leukaemia.

We regularly send updates on project performance and outcomes to our supporters through an e-newsletter as well as publish updates on our social media channels, news articles on our websites and submit press releases to the local media companies. We have appeared on BBC East Midlands Today and ITV News.

Financial Review

Income from donations and fund-raising activities for the year amounted to £129,778 (*2020: £201,178*). Bank interest received in the year amounted to £10 *(2020: £126).*

Expenditure incurred is as shown on the detailed statement of financial activities and included: expenditure on fund-raising activities which amounted to £7,666 *(2020: £18,277).*

Overheads include payments for administrative services and the management of events and fundraising activities of £45,386 (35% of total income) *(2020: £48,601; 24% of total income)* and other costs relating to

promotional materials, Trustee expenses, insurance, bank charges, marketing, bookkeeping, and networking events of £7,451 *(2020: £15,877)*. To help with the increasing administrative, event management tasks and liaison with our supporters the Trustees use the services of a full-time employed person – working five days per week plus a part-time employed Events Co-ordinator. Total operating costs equates to 41% of total income raised (32% in previous year).

Payments towards research and clinical trials amounted to £62,142 *(2020-£75,000)* see breakdown below. Overall, there were net incoming resources for the year of £31,503 (*2020: net incoming resources of £49,743)*.

Our Impact

The Trustees are delighted that they have been able to make payments during this accountancy period to three projects equating to £62,142 to various scientific research projects and to increase clinical trial capacity in the UK in line with its objectives. Whilst this is lower than we had forecasted as a Charity we remain strong and took the decision during 2020 to hold onto funds to ensure the Charity could withstand the duration of the Pandemic. See below a breakdown of these projects:

- **Project 1 - A post held at Newcastle University, Dr Michela Guglieri, the fifth and final year - £7,142**
- **Project 2 – We have invested £30,000 into a Phase 2 Clinical Trial Study of Edasalonexent in older boys (non-ambulant population) not currently taking steriods** - Undertaken by Catabasis Pharmaceuticals to investigate if Edasalonexent is safe and efficacious treatment for Duchenne in the non-ambulant population, with a similar pharmacokinetics and safety profile as previously demonstrated in young boys, and with positive effects on skeletal muscle, as well as respiratory and cardiac function while maintaining an excellent safety profile. Edasalonexent is a potential alternative to steroids, and we hope that it will avoid many of their unpleasant side effects. This trial was important as it focussed on the non-ambulant patients which is particularly important for older patients with Duchenne who usually can't enrol in other clinical trials, which tend to be targeted at younger patients. This was a 3-year project to be completed by March 2022. Shortly, after investing in this project, we received new that the original trial had failed to meet both its primary and secondary endpoints and that all trials relating to this due will be stopped. As a result, the funded given to Duchenne UK for this project, was no longer required for this study. Rather than giving Alex's Wish the funds back, we consulted with Duchenne UK, and it was agreed for them to hold onto this investment and Alex's Wish would decide which new projects to invest the funds into.
- **Project 3 – We have invested £20,000 into Lipid Nanoparticles Technology** – successfully used in the recent Moderna and Pfizer/BioNTech COVID-19 vaccines this could be used for gene therapy, lipids (LNP's) are naturally occurring small fatty molecules that exist within the body. Several trials on gene therapy are underway using harmless viruses called AAV's, to deliver synthetic gene to replace the faulty dystrophin gene in Duchenne. However, some patients will have pre-existing antibodies to the virus and will not be eligible for treatment. This study aims to address these challenges by exploring LNP's as a method of delivering gene therapy.

As explained earlier in this report, during this accountancy period, the decision was taken to reallocate £73K of monies raised by Alex's Wish and currently unspent by Duchenne UK into the projects listed below:

- **Project 1 – We re-invested £5,000 funds into in a new research study - Lipid Nanoparticles** (this is the same project as mentioned above).
- **Project 2 – We re-invested £3,000 funds into a new research project to address the lack of accessible housing** - one of the biggest barriers to living an independent life as a disabled person is the lack of suitable, accessible housing. Partnering with Pathfinders Neuromúscular Alliance, a charity run by and for adults with muscle-weakening condition, to address the lack of choice, shortage, and control over accessible housing for people living with Duchenne. Through a series of focus groups and surveys, they aim to identify the housing needs and their families and explore the current barriers.
- **Project 3 – We re-invested £10,000 into a new research project to improve the knowledge of heart care in Duchenne patients** - almost all people with Duchenne will develop heart disease, there are drugs believed to slow down damage and protect the heart. However, no clear data exists for their effective use in Duchenne. In 2011, a clinical trial called The Heart Protection Study was set-up to see

if starting two existing heart medications in combination could protect the heart. The results didn't show clear evidence either way. This further study to follow-up on those boys who took part in the trial and collect data since the trial ended in 2018, an additional 3 years of heart reviews collected on their regular check-ups. This should give us a clearer picture of the impact these drugs have had, if the data suggests they do help, it will lead to them be routinely prescribed earlier in boys with Duchenne.

- **Project 4 – We re-invested £15,000 into diagnosing cardiac fibrosis in female carriers of Duchenne** – working with Dr Lee Borthwick and Dr John Bourke at Newcastle University, the aim of this project is to find quicker ways of diagnosing cardiac complications in mothers who carry the Duchenne gene. The project commenced on 1st October 2020. During the first 5 months of the Study, they have obtained samples from 17 patients. Recruitment of the remaining 18 patients is ongoing and progressing well. Once all samples have been acquired the downstream analysis will begin. The study commenced on 1st October 2020 and good progress has been made in the recruitment of samples despite the challenge of the COVID-19 Pandemic. Currently we do not anticipate any challenges in completing the study within the scope of the award.
- **Project 5 – We re-invested £40,000 to help expand access to clinical trials in the UK: by funding a DMD Hub Manager post for 4 years** - over the past few years, Alex's Wish has invested £119K though The DMD Hub helping ensure patients in the UK with Duchenne, have access to clinical trials. A clinical trial is often the families only hope of accessing potential new treatments that might one day become approved medicines. When we learnt that clinical trials were being turned away from UK hospitals, because of the lack of doctors, nurses, and physiotherapists to run them, a collaboration of several Duchenne charities collaborated to form the DMD Hub, Alex's Wish being one of them. The DMD Hub has already helped 437 boys get onto clinical trials since 2015. Additionally, 11 UK hospitals are conducting 20 trials into potential treatments for DMD, with 8 new trials opening in 2021. It was cited as an excellent example of digital infrastructure in a recent report by the Association of Medical Research Charities. Emma Heslop is the DMD Hub Manager and is key to the success of this project and she ensures patients are appropriately represented as key stakeholders in all aspects of the DMD Hub. Emma has direct access to clinicians and industry partners through the relationship she has cultivated over the years. As the main point of contact for all companies with trials coming to the UK, she also promotes the UK as an attractive place to run DMD trials and works with them to support site selection and patient recruitment. Her role also involved co-ordinating the staff networks for clinical trial coordinators, nurses, and lead clinicians, which include staff from across all eleven DMD Hub sites. These networks promote communication between the different sites so that they can share best practice and expertise. They also highlight any training needs, which The DMD Hub can then help to deliver. Her workplan over the next 4 years includes several exciting projects, which will have a significant impact for the Duchenne community. This grant will help support the funding costs of the DMD Hub Manager for another 4 years and will play a crucial part for the continuing success of the DMD Hub. Without the funding of charities like Alex's Wish, Emma Heslop would not be able to carry on with this role and the impact would be significant.

We provide project updates and when they become available on our website. Please visit www.alexswish.co.uk for more details.

Our Major Achievements

- Co-funded 27 projects across a broad-spectrum from early-stage research through to clinical trials as well as invested in 5 clinical posts to help further our mission.
- **We invested £30,000 in pioneering Pluripotent Stem Cell Therapy 'Altering the muscle environment to influence stem cell behaviour' at The University of Minnesota** which is looking at regenerating muscle in Duchenne patients with stem cells. Stem cells are a potentially exciting approach to generate new healthy muscle in patients with Duchenne. The stem cells we are looking at are called human induced pluripotent stem cells (iPSCs). These cells replace the diseased muscle tissue with stem cells that can create healthy myofibers which are able to regenerate. The aim of this project is to produce and test these stem cells to get the preclinical data required to progress to a clinical trial. The team will use our grant to test several things including what dosing should be used and the safety and toxicity. If the project is successful, the group will commence planning for a Phase I Clinical Trial to start testing this approach on patients. This project, which Alex's Wish is helping to support, is aimed

at the first stages of scale up transfer. In effect, the proposal concerns the transfer of this technology to the University of Minnesota Translational Cell Therapy Facility. This project has been moving well considering the COVID impact and Aim 1 of the Study has been achieved. Prof. Rita Perlingeiro, will now conduct experiments in a mouse model to ensure safety/efficiency outcomes.

- **We invested £30,000 to fund a PhD post at The John Walton Muscular Dystrophy Research Centre at Newcastle University** specifically to look at the FOR-DMD Study (finding the optimum Steriod regime for boys living with Duchenne) supervised by Dr Michela Guglieri. The PhD post will ensure that the data generated by the FOR DMD study will be used to address new clinical and research questions.
- **We invested £15,000 in helping improve the success rate of clinical trials (PC Slices)** - this project is working with Professor Mann and Dr Borthwick from the Newcastle Fibrosis Research Group in the University Biosciences Institute. We had some devastating news at the end of 2019: the early termination of a clinical trial run by Wave Life Sciences. The news was a big blow, not least because early data in animals had shown that the drug was effectively producing dystrophin. How could a trial that showed such a promise in animal models not deliver results in humans? Early-stage tests are done on mice with Duchenne and then transferred to trials in people – but there is uncertainty whether a drug might behave the same in the human body. We want to stop this. That's why we supported this project, which has the potential to help us understand, at a much earlier stage of research, whether a medicine will help treat Duchenne patients. We received a full report on the Study in August 2021, the project has been hit by a reduction in elective surgeries and heart transplants due to COVID, but some material and analysis was still able to take place. The analysis of the human hearts slices has allowed the researchers to identify pathways involved in inflammation and fibrosis in the heart and began to explore whether these pathways are possible therapeutic targets to reduce cardiac inflammation and fibrosis. The next steps of the project are to look at potential molecules that affect these pathways in the human heart slices, to determine whether any of these compounds could be repurposed to reduce the development of inflammation in the heart. A full report on progress is expected in 2022.
- **We invested £50,000 into helping accelerate Gene Therapy with Solid Biosciences through their IGNITE DMD Phase I/II Clinical Trial for SGT-001 with Solid Biosciences** – we were told gene therapy would not happen in our lifetimes. But we did not accept that. We are pleased to say this gene therapy programme is now in clinic in the US being tested on boys with Duchenne. Gene therapy offers hope as a potential treatment for Duchenne. We are extremely proud to have played a part in helping to accelerate the development of gene therapy. Solid Biosciences continue to work with urgency and scientific rigor to advance SGT-001. They were recently pleased to share that they had successfully dosed the ninth patient in the IGNITE DMD study in November 2021 and plan to continue dosing in 2022. We look forward to hearing further updates in due course.
- **We invested £35,710 over a 5-year period (2015-2020) into a Duchenne Muscular Dystrophy Clinical Trials Lectureship post (Dr Michela Guglieri)** – and we are delighted to report the outcomes of this grant, which was supported by a consortium of seven UK charities, Alex's Wish joined by Duchenne UK, Action Duchenne, Duchenne Research Fund, Duchenne Now, Duchenne UK, Harrison's Fund and Joining Jack to invest a total of £250,000. The Clinical Trials Lectureship grant enabled Dr Michela Guglieri to act 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 research centres, that ensures trials are run smoothly and safely, and generate good quality data. The project has supported the establishment of a strong clinical research team at the John Walton Muscular Dystrophy Research Centre and of national and international collaborations and networks which will play a key role in ensuring the clinical research in Duchenne Muscular Dystrophy will continue to come to the UK and to establish the UK as an expert and efficient country to deliver best care practice and clinical research. Since May 2017, as well as training and supporting the staff in the clinical research centre, over the course of the grant, Dr Guglieri has led 10 clinical trials in Duchenne, including The FOR DMD Study and The Vision DMD Trial, testing the safety and effectiveness of Vamorolone – a potential drug that researchers hope could offer some of the effects of steroids with fewer side effects. The support from the 7 different charities has not only resulted in significant impact during the years of funding, but also a permanent position for Michela through Newcastle University. In this role, she will continue to work as Clinical Research Lead, supporting clinical research activities as well as national and

international collaborations to improve care, treatment and research opportunities for people living with Duchenne muscular dystrophy.

- **We invested £37,000 into a Heart Study (Arrythmias) with Professor John Bourke at Newcastle University -** all patients with Duchenne will ultimately be affected by progressive cardiomyopathy and as Duchenne patients' life expectancy increases, this becomes a key element of survival in later life. If the pump function in the heart is severely reduced there can be a range of symptoms including fast / slow rhythms and severe fibrillation. This can result in unheralded collapse and is the most common cause of death following myocardial infarction. However, outwardly similar collapse can be caused by heart stoppage / complete AV heart block and, in patients with advanced heart failure, clots can develop due to poor blood flow resulting in pulmonary embolism. The thing to note is that many of these outcomes would be outwardly indistinguishable and death can occur when a patient has been previously apparently stable. In October 2020, we received an update Dr Bourke and his team are looking to see if using implantable devices, such as defibrillators or pacemakers, could prevent future cardiac arrests, by detecting 'background arrhythmias'. Treatment with these devices is known to help non-Duchenne patients with similar degrees of heart pumping weakness to live longer. However, implantable defibrillators are not usually considered for patients with Duchenne. This project has been disrupted by the Pandemic, with recruitment being placed on hold after only four patients had been enrolled. One of the members of the project team also had to be redeployed to assist with the NHS' COVID-19 response. Now restrictions are easing, they are in the process of completing recruitment for another two patients and are working to identify more patients to take part in the study.
- **We invested £60,000 into a research project to study an alternative gene therapy delivery method with EVOX Therapeutics. The collaboration with EVOX on exosomes has been completed early. We have successfully demonstrated mRNA loading but optimising this process requires further work by EVOX alone.** In September 2018, we co-funded this project alongside Duchenne UK to investigate using exosomes, a potential alternative to using viruses, to deliver gene therapy. Exosomes are nanoparticles that all cells release, and which contain proteins and other large molecules. They are the body's natural way of effectively, safely, and repeatedly delivering molecules from cell to cell, and even crossing the blood brain barrier to access the brain. The aim of this project was to see if exosomes could be used to deliver gene therapy to muscle cells. Several companies are now testing gene therapy in Duchenne, by using viruses to deliver the micro-dystrophin. However, many people with Duchenne may have pre-existing antibodies to the viruses being used to deliver gene therapy, which makes them ineligible for this treatment. Similarly, patients receiving viral gene therapy would develop immunity making repeated dosing, if required, impossible. We collaborated with EVOX – to look at ways of making gene therapy available to all patients. During this collaboration, EVOX has been able to load mini- and micro-dystrophin mRNA into exosomes (for technical reasons full-length dystrophin was not available for testing). EVOX has decided to carry out further optimisation of its mRNA loading approach work itself (and at its own cost) before then directing it towards the treatment of a variety of muscular skeletal diseases, including potentially Duchenne. Consequently, this work has been completed early. We carefully fund projects in staged payments so the remaining funds for this project (£43,000) has been re-distributed.
- **We invested £10,000 into a Testosterone extension study to address delay in puberty due to steroid use in Duchenne and improving wellbeing in teenagers** – steroids are part of the recognised standard of care in treating Duchenne, but long-term use of steroids causes several side effects including delayed puberty. Testosterone is sometimes given to make boys begin going through puberty. It may also have other benefits. As the life expectancy of Duchenne patients' increases more young men are looking to establish relationships and lead independent adult lives. We are funding this research to ensure boys are given the correct hormonal treatment to allow them to develop properly. Our funds will support the clinical trial at the John Walton Muscular Dystrophy Research Centre (JWMDRC), led by Prof Volker Straub and Dr Claire Wood, treating 15 adolescents with Duchenne with testosterone to induce puberty. As well as looking at the effect of testosterone on pubertal development, growth, muscle strength and function, bone mineral density and body composition, the trial is looking at the mood, quality of life and well-being of patients to assess their satisfaction with the benefits of the treatment compared to the side effects. This project has seen delays due to COVID, as boys were unable to attend regular hospital in-clinic appointments.

- **We invested £25,000 into a cancer drug showing promise as a treatment for Duchenne (TAMDMD) – Tamoxifen, a drug to treat breast cancer, could be an effective treatment for Duchenne.** Using medicines already approved for other conditions to treat DMD is a key focus on what we fund. It's known as drug-repurposing and is attractive because it means potential medicines can be tested in clinical trials in far shorter timeframes. Tamoxifen is a cheap and readily available medicine, with a good safety record in adults. If this trial was to be successful, we could see a cheap, effective, and readily available treatment for Duchenne in the very near future. This is a great example of a repurposing drug, which is an exciting approach to drug development. It involves looking at medicines and testing them to see if they could be effective in treating Duchenne. Whilst more than 30 patients have been dosed, we have received preliminary data from the trial. The data, which compared disease progression in a group of boys receiving Tamoxifen to that in a group receiving a placebo, has now been analysed following completion of the initial stages of the trial. This analysis found that over the 48-week trial period, patients in both the tamoxifen and placebo group showed mild disease progression against all clinical and MRI endpoints. While there was a trend for less disease progression in the tamoxifen group, the differences between the two groups were not large enough to determine if tamoxifen was effective in delaying disease progression. Further analysis of the data is ongoing, with investigators specifically looking to try to understand why the group of boys receiving placebo did not progress as much as would have been expected – a result which contributed to the small difference between the two groups. The data has however shown that across this trial and the follow-on open label extension, there have been no safety concerns so far and the drug has been generally well tolerated. Based on these initial data though, the clinical team have concluded that the trial did not meet its primary goals. These preliminary results have now been communicated to all trial sites and participants and further discussion around the data and next steps for those boys who are still enrolled in the open label extension study are ongoing. Clinical decisions for this group will be made in conjunction with participants and their families based on review of all available clinical information.
- **We invested £35,000 into The SOLID Suit** - harnessing military technology to create wearable support for Duchenne patients. We're working hard to develop drugs to end Duchenne. But we're also trying to support people living with the condition. One project we're delighted to contribute to is the SOLID suit. Solid Biosciences is working with experts to develop soft, wearable, assistive devices for patients, to help them perform day to day activities more easily. It uses cutting-edge military technology to power soft exoskeletons to support muscles.
- **We have committed £83,913 in three clinical posts to increase clinical trial capacity in the UK** - through the DMD Hub, helping ensure all patients in the UK with Duchenne, both children and adults, have access to clinical trials. A clinical trial is often a family's only hope of accessing potential new treatments that might one day become approved medicines. When Duchenne UK learnt that clinical trials were being turned away from UK hospitals, because of lack of doctors, nurses, and physiotherapists to run them, they alongside patient led charities like Alex's Wish collaborated to change this and the DMD Hub was formed. The Hub has already helped increase the number of UK sites which run Duchenne trials. We are extremely passionate about this project as it increases the opportunity for boys with Duchenne to get onto a clinical trial should they wish too.
- **Invested £47,000 into Vamorolone, a steriod-alternative drug** – their recent Phase 2b study has been completed and is proud to announce the success of the clinical study programme for Duchenne. This project started in 2016, and almost 6 years on, the Phase 2a and Phase 2b clinical studies have been a success story.
- **We gave a £10,000 grant to the Heartlands Hospital Charity in Birmingham** to help facilitate better access for children to the research trials. The money helped them purchase a large double plinth and a padded floor mat for the children to lie on for the therapy assessments. They also provided a manual wheelchair which means that they can transport ambulant children between the therapy department and the research centre. These pieces of equipment have been extremely useful and helped them to optimise their assessments and management of the children and young people with Duchenne. The funding also helped them to fund research time for a consultant doctor to increase the centre's ability to conduct clinical trials which has been invaluable to their service.

- **In addition, we have won seven prestigious awards in the East Midlands region and have been a finalist in a prestigious national charity award.**

Strategic Approach and Future Plans

Our strategy is to attract as much funding as possible, through the following core activities:

- Attract new businesses to our cause to ensure we have a pipeline of income scheduled for at least 12 months ahead.
- Increase the number of touchpoints with new and existing supporters to demonstrate the impact made to our beneficiaries and to outline our future goals and fundraising initiatives. This included our hugely successful Supporters Thank You Lunch at The Novotel Hotel in October 2021 which was generously sponsored by Nelsons Solicitors, Janine Edwards Wealth Management, Spirit Healthcare and Brand Clear. This event saw 170 supporters from across the region attend our event to hear about the impact of the work Alex's Wish has had on families affected by Duchenne and from Emily Crossley, Co-Founder of Duchenne UK and to find out about our plans and how they could get involved further. We also organised an **Un-Masquerade Celebration** in November 2020, you can view our **Supporters Update video.** We also arrange 1-2-1 meetings with our business supports to keep in touch and update them on our progress.
- Develop new and existing fundraising streams and activities. Throughout the Pandemic we have been creative in our approach and tested new online virtual events including the My Prudential Ride London, virtual cycle rides and marathons, virtual ethical Business Club meetings, virtual concerts and many more. This has enabled us to continue raising funds despite not being able to organise our traditional events. We are very proud of our team for being innovative and open to new ideas.
- Increase our level of income each year by building relationships with our existing supporters as well as attracting new supporters to our cause.
- Continue to review operating costs and resources ensuring it is in line with our objectives. When the Pandemic hit, we stripped out costs where we could and made use of the Government's furlough scheme to reduce employee costs.
- Continue to fund projects that will bring about effective treatments for Duchenne and aim to invest a minimum of £150,000+ per year. Whilst our aim has always been to fund quickly as soon as we have £25,000-£30,000 available our Board of Trustees took a cautious approach to funding in this accounting period to ensure the sustainability of the charity in future years. Whilst we were not able to invest £150,000 during this accountancy period, we were able to fund £62,142 and have now built-up sufficient reserves (£200K) to release funds into projects to further our mission very shortly.
- Raise awareness and increase our visibility across the East Midlands region. During the Pandemic we have seen a fantastic amount of PR coverage within the region we operate in and have appeared on BBC East Midlands Today and ITV News as well as done various interviews with BBC Radio Leicester. We continue to generate lots of newspaper and magazine coverage with our news stories including supporter fundraising initiatives and project funding updates.

In the coming year we plan to:

Objective 1: To identify, fund and monitor medical research projects, clinical trials, and clinical trial capacity Projects

- To receive updates on outcomes for all projects funded so we can report on the impact those projects have made to help progress our mission. To report on these via our news feeds on our website, social media, e-newsletters to our supporters and through local press coverage.
- Continue to work closely with Duchenne UK as a Charity Partner, to seek out and fund new and exciting clinical trials, research projects and clinical trial capacity as and when it arises ensuring that our funds are spent effectively and in the right areas to help bring about the best chances of bringing new treatments to market. At the time of writing this report we have identified four new projects we would like to fund utilising the funds currently available in our savings account.

Objective 2: To continue lobbying government and other regulators and to engage with media and our supporters to raise awareness of Duchenne Muscular Dystrophy

- Attend national events and meetings to help lobby MPs and Parliament to bring about new treatments to market as quickly as possible e.g. Translarna.
- Attend Duchenne Parent Days run by Duchenne UK and the National Action Duchenne Conference to engage with other parents affected by Duchenne Muscular Dystrophy, as well as keep abreast of latest progress made in the field of Duchenne.
- Continue to write press releases and submit to the local press in the East Midlands to help raise awareness about the work we are doing and its impact on the local community / the rest of the UK and to help attract new supporters to our cause.
- Continue to send regular updates to our supporters via e-newsletters, website and social media and keep interest and support our ongoing work.
- To organise Supporter events such as our annual Supporters Thank You Lunch and virtual events to keep in touch with our supporters about the vital work that we do.
- Continue to attend networking events within the region to build new and foster existing relationships and attract new supporters to our cause.

Objective 3: Fundraise through our flagship events, supporter events and fundraising activities:

- Organise flagship events: Charnwood Forest Cycle Ride (10-, 20- or 50-mile cycle ride), Golf Day, Supercars event, and our Annual Fundraising Ball and support other organisations and individuals organising events in support of our goals.
- To attract supporters to take part in the Prudential Ride London, London Marathon, Sky Dives, Quiz Nights, family-fun walking and running events, virtual events, challenge events e.g., Zipwire challenges, Sky Dives, Loop the Loop, and Abseil Challenges.
- We aim to work within a 30:70 ratio of cost of an event to income received from an event to ensure that 70% of what we raise from our events overall goes directly to potential life-saving treatments. We would like to attract more capital through corporate sponsors to cover off most of our event costs to help bring this ratio down as low as possible. We have been successful in attracting corporate sponsors and will continue to build those relationships.
- Majority of our income raised has been through hosting our own events. Our aim is to continue working with local businesses to take Alex's Wish on as their chosen charity and organise their own events and consider Alex's Wish as their Charity of the Year. This means that 90%+ of the money they give to us as a Charity goes directly to life-saving treatments as they do not incur the expenditure that our own fundraising activities require.
- Continue to work closely with Miss Great Britain who has chosen Alex's Wish as one of their two charities to support in 2020, 2021 and 2022 and will work closely with all the ladies to help with their personal fundraising initiatives.
- Continue to promote our 'Be More Alex' campaign designed to attract regular givers to give £7 per month to our cause.
- Continue to grow our 'Ethical Business Club' by attracting local organisations to support our cause through a regular donation in exchange for business benefits such as organising local networking events to bring the local business community together. Continue to retain our sponsors.
- Form strategic alliances and partnerships with organisations such as local sporting clubs, colleges, schools, and corporate businesses. More recently we have been taken on as a Charity of the Year at The Leicestershire Cricket Ground, and The Leicestershire University and look forward to working closely with them.
- Continue to attend local networking groups throughout Leicestershire and the East Midlands with the primary aim of building relationships and raising awareness of Duchenne amongst the local business community.
- Continue to be a member of the East Midlands Chamber of Commerce.
- To continue to reach out to local trusts and foundations with the view to them helping us cover our fixed costs such as administration through grants.

Structure, Government and Management

The organisation is a charitable company limited by guarantee, incorporated on 22 June 2012. The company was established under a Memorandum of Association which established the objects and powers of the

charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £10.

The body responsible for management of the Charity is the Board of Trustees of Alex's Wish. The Board meets monthly (and at least ten times per year). The charity's constitution is set out in the Articles of Association, and all Trustees have agreed to this. New Trustees are appointed by the existing Board of Trustees. Trustees give of their time freely and no Trustee remuneration was paid in this year. Details of Trustee expenses and related party transactions are disclosed in the accounts. Trustees are required to disclose all relevant interests and to withdraw from decisions where a conflict of interest arises. None of the Trustees have any interests with the pharmaceutical industry.

We regularly review our stated aims, objectives, and activities to ensure we are working toward our stated purposes. We have referred to the guidance contained in the Charity Commission's general guidance on public benefit under the Charities Act 2011 when setting and reviewing our aims and objectives and in planning our future activities. All our charitable activities focus on improving the lives of those with Duchenne Muscular Dystrophy and research into the disease.

Trustee Recruitment

Trustees will be recruited through advertising in local newspapers, and through social media, at our events and through word of mouth. Those expressing an interest will, in the first instance, be met by the Charity Founder, given an overview of the organisation, and encouraged to apply. The Chair and another trustee will examine the applications against the most recent skills audit, produce a short list, and invite those on it to submit their references and then attend an interview; the Chair and another trustee will conduct the interviews, and make recommendations to the Board. At its next meeting, the Board will review these recommendations, and either ratify or reject. Successful applicants will be asked to complete and sign the declaration of interest form, sign a declaration that they are eligible to serve as a trustee; and agree to the code of conduct. They will then become a trustee of the Board.

Risk Management

The Trustees continue to review the major strategic, business, and operational risks which the charity faces and confirm that systems are in place to enable regular reports to be produced so that the necessary steps can be taken to lessen these risks. In assessing risk, the Trustees recognise that some areas of the work require the acceptance and management of risk if the charity is to achieve its objectives.

During the Pandemic, the Board of Trustees have taken a cautious approach to funding research projects however this is currently being reviewed now that we have sufficient funds in place to ensure the charity remains sustainable.

Basis of Preparation of Accounts

The accounts have been prepared in accordance with the accounting policies set out in note 1 of the accounts and comply with the charity's governing document, the Companies Act 2006 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) (as amended for accounting periods commencing from 1 January 2016).

Financial Reserves Policy

The Charities SORP requires a charity to state the amount and type of financial reserves it holds, and to compare how the level of those reserves matches up to "The level of reserves the trustees feel as appropriate given their plans for the future activities of the charity". Where it falls short, the trustees need to explain what steps they are taking to rectify the situation. In this context, the charity views financial reserves as those held in its unrestricted funds, the balance of funds stood at £140,163 at the year-end (2020: £108,660). The Trustees establish the appropriate level of unrestricted reserves (over and above those already ring-fenced for future plans, or known liabilities within restricted and designated Funds) by seeking to ensure that the level of the charity's 'free reserves' meets a chosen benchmark related to the budgeted expenditure for unrestricted activities. The Trustees consider the "free reserves" to be the unrestricted funds not committed or invested in tangible assets. As a result of a full and objective review of its 'free reserves' policy, taking into account all the

risks foreseeable at that point and the charity's approach to their mitigation, the Trustees agreed on 18th February 2021 that a minimum level equivalent to three months' budgeted expenditure plus a £5,000 reserve for event reservation should be maintained as 'free reserves'. This level has continued to be reviewed for adequacy and robustness to ensure the Charity maintains adequate finances to meet day-to-day operating costs, and we will continue to review this over the coming months. As of 30 June 2021, the Charity's "free reserves" stood at £140,163 (2020: £108,660), resulting in a surplus of £120,163 (2020: surplus of £88,660) when compared with the current benchmark, calculated as £20,000.

Statement of Trustees' Responsibilities

The Trustees (who are also Directors of Alex's Wish for the purposes of company law) are responsible for preparing the Trustees' report and the accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare accounts 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 accounts, the trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP;
- Make judgements and accounting estimates that are reasonable and prudent;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- Prepare the accounts on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the accounts 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.

This report was approved by the Trustees on 30th March 2022 and signed on their behalf by

EHallam.

Mrs EJ Hallam

Independent Examiner's Report to the Trustees of the Alex's Wish

I report to the charity Trustees on my examination of the accounts of Alex's Wish for the year ending 30 June 2021, which are set out on pages 19 to 23.

Responsibilities and basis of report

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

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

Independent examiner's statement

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

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)

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

30th March 2022

TD Fowler BA FCA
Chartered Accountant for
HSP Tax & Accounts Ltd
Whiteacres
Cambridge Road
Whetstone
Leicestershire
LE8 6ZG

Statement of Financial Activities

For the year ended 30 June 2021

	Note	Unrestricted funds 2021 £	Total 2020 £
Income from:			
Donations		**28,979**	44,690
Fund-raising activities		**100,799**	156,488
Bank interest received		**10**	126
Grants received		**24,360**	6,194
Total income		**154,148**	**207,498**
Expenditure on:			
Charitable activities	2	**(122,645)**	(157,755)
Net income/(expenditure) for the year/net movements in funds		**31,503**	49,743
Fund balances at 1 July 2020		**108,660**	58,917
Fund balances at 30 June 2021		**140,163**	108,660

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

Balance sheet

At 30 June 2021

	Notes	2021 £	2021 £	2020 £	2020 £
Current assets					
Debtors	3	**17,222**		16,623	
Cash at bank and in hand		**134,898**		95,731	
		152,120		112,354	
Creditors:					
Amounts falling due within one year	4	**(11,957)**		(3,694)	
Net current assets			**140,163**		108,660
Total assets less current liabilities			**140,163**		108,660
Funds					
Unrestricted funds	5		**140,163**		108,660
Restricted funds	5		-		-
Total Funds			**140,163**		108,660

For the year ending 30 June 2021 the charitable company was entitled to exemption from audit under Section 477 of the Companies Act 2006.

The Trustees acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply with section 386 of the Companies Act 2006 and for preparing accounts which give a true and fair view of the state of affairs of the charitable company as at the end of the financial year and of its incoming resources and application of resources, including its income and expenditure, for the financial year in accordance with sections 394 and 395, and which otherwise comply with the requirements of the Companies Act 2006 relating to accounts, so far as applicable to the charitable company.

The members have not required the charitable company to obtain an audit of the accounts for the year in question in accordance with section 476.

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

These financial statements were approved by the Trustees on 30th March 2022 and were signed on their behalf by:

EHallam.

Mrs EJ Hallam
Trustee and Director

Notes

(forming part of the unaudited financial statements)

1 Accounting policies

Company status

Alex's Wish is a private company limited by guarantee. The registered office is 20 Granite Way, Mountsorrel, Leicestershire, LE12 7TZ. The members of the company are the Trustees as detailed in the Legal and Administration information who are also the Directors of the company for company law purposes. In the event of the charity being wound up the liability in respect of the guarantee is limited to £10 per member of the charity.

Accounting convention

The accounts have been prepared in accordance with the charity's governing document, the Companies Act 2006 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) (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP the charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

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

These accounts have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

Going Concern

The financial statements have been prepared on a going concern basis. Having carried out a detailed review of the Charity's resources and the challenges presented by the current economic climate, the Trustees are satisfied that the Charity has sufficient cash flows to meet its liabilities as they fall due for at least one year from the date of the approval of the financial statements. The Charity has undertaken a detailed exercise to forecast the ongoing financial impact of Covid-19 on its future liquidity out to 31 March 2022. In parallel it has reassessed all operations and business plans and has controlled spend and activity during the year as well as taking advantage of government support, such as the Coronavirus Job Retention Scheme. The cash flow forecast, and revised plan shows that the Charity will have adequate reserves and will be able to meet its liabilities. Accordingly, the Trustees do not consider there to be any material uncertainties and continue to adopt the going concern basis in preparing the financial statements as outlined in the Trustees' Responsibilities Statement. There are no significant financial uncertainties that the Trustees consider are a significant risk to the ability of the Charity to trade as a going concern in the foreseeable future.

Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used.

Incoming Resources

All income is recognised when the charity has entitlement to the funds, it is probable that the income will be received, and the amount can be measured reliably

Incoming resources relating to specific events are recognised in the accounting period in which the event takes place.

Resources Expended

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Support costs are those costs incurred directly in support of expenditure on the objects of the charity and include project management carried out.

Costs relating to specific events are recognised in the accounting period in which the event takes place.

There were no employees whose annual renumeration was more than £60,000.

Financial instruments
The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transactional value and subsequently measured at their settlement value.

Taxation
The charity is exempt from corporation tax on its charitable activities.

Grants
Grants are credited to deferred revenue. Grants towards capital expenditure are released to the profit and loss account over the expected useful life of the assets. Grants towards revenue expenditure are released to the profit and loss account as the related expenditure is incurred.

2 Charitable Activities

	2021	2020
	£	£
Payments for research and clinical trials	**62,142**	75,000
Expenditure on charitable events	**7,666**	18,277
Administrative services	**45,386**	48,601
Other expenses	**7,451**	15,877
	122,645	157,755

3 Debtors

	2021	2020
	£	£
Amounts owed for event income	**244**	244
Trade debtors	**280**	-
Prepaid event costs	**16,698**	16,379
	17,222	16,623

Notes - continued

(forming part of the unaudited financial statements)

4 Creditors: amounts falling due within one year

	2021	2020
	£	£
Income received in advance of events	11,957	3,694

5 Movement in Funds

	At 30 June 2020	Net movement in funds	At 30 June 2021
	£	£	£
Unrestricted funds	108,660	31,503	140,163
Restricted funds	-	-	-
Total Funds	108,660	31,503	140,163

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds	154,148	(122,645)	31,503
Restricted funds	-	-	-
Total Funds	154,148	(122,645)	31,503

6 Employees:

	2021	2020
Average number of employees during the year	2	1

Employment costs:

	2021	2020
	£	£
Wages and salaries	43,873	23,250
Pension costs	1,316	698
	45,189	23,948

Detailed Statement of Financial Activities

for the year ended 30 June 2021

	2021 £	2021 £	2020 £	2020 £
INCOMING RESOURCES				
Incoming resources from charitable activities				
Donations		**28,979**		44,690
Fund-raising activities		**100,799**		156,488
Total incoming resources		**129,778**		201,178
RESOURCES EXPENDED				
Charitable activities				
Charitable event expenditure:				
Big Xmas give	**164**		-	
Golf Day	**-**		4,156	
Coast to coast ride	**1,419**		-	
Tour de Alex	**72**		-	
Prudential Ride London	**560**		-	
Annual Fundraising Ball	**-**		10,157	
Masquerade Ball	**3,169**		-	
Ethical Business Club	**335**		466	
The Brothers Trust	**324**		-	
Super cars event	**270**		-	
Be More Alex regular giving campaign	**632**		-	
Art Exhibition event	**-**		2,380	
AGM/Supporters Thank You Lunch	**649**		-	
Kreative Group's Miss GB Finals Event	**-**		70	
Virtual 'Take That' Night	**-**		120	
Leicestershire Cricket Ground Fireworks Night	**-**		817	
Leicestershire Law Society Zipwire Challenge	**-**		39	
Other sundry event costs	**72**		72	
		(7,666)		(18,277)
Net proceeds from charitable activities		**122,112**		182,901
Overheads				
Administrative services:				
Event management	**31,770**		34,621	
Administration	**13,616**		13,980	
Business development and networking events	**3,780**		10,174	
Promotional material	**424**		2,178	
Website & email marketing	**38**		-	
Bookkeeping and legal fees	**223**		198	
Postage, stationery & office expenses	**-**		63	
Insurance	**445**		513	
Bank charges	**185**		311	
Computer and software costs	**2,356**		2,440	
		(52,837)		(64,478)
Bank interest received - gross		**10**		126
		69,285		118,549
Payments for research and clinical trials		**(62,142)**		(75,000)
Government grants received		**24,360**		6,194
Net incoming/(outgoing) resources		**31,503**		49,743

This page does not form part of the unaudited accounts.