

**Alex's Wish**

**Company Limited by Guarantee**

**Trustees report and unaudited financial statements**

**Registered company number 08116159**

**Registered charity number 1148845**

**30 June 2022**

**ALEX\*s WISH**  
cure Duchenne

## Contents

Legal and Administration Information	1
Trustees Report	2-17
Independent Examiner's Report	18
Statement of Financial Activities	19
Balance Sheet	20
Notes to the Financial Statements	21-23
Detailed Statement of Financial Activities	24

## 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](http://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 1<sup>st</sup> September 2021)
- Alexandra Slack, Chair and Trustee (Appointed as Chair 1<sup>st</sup> September 2021)
- Chris Everard, Trustee
- Rachel Hargrave, Trustee (Resigned 1<sup>st</sup> 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](http://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 Riccotti
- 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, 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 its 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 steroids - 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 arms. 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 6<sup>th</sup> 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 (1<sup>st</sup> July 2022 - 30<sup>th</sup> 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 bring 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 30<sup>th</sup> 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](http://www.alexswish.co.uk) and our World's Strongest Boys video [https://youtu.be/0uxxh3xk0\\_g](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-RRIMhQmKhBhNylsS6hZA>
    - Linked In** <https://www.linkedin.com/company/9202750/admin/>
    - Instagram** <https://www.instagram.com/alexswish/>
  - 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](http://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 fast, reliable and cost-effective. The biomarkers need to be tested in cohorts of female carriers, as well as make Duchenne patients, to be fully validated. 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 allow 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-alex-s-wish-helps-fund-duchenne-muscular-dystrophy-dmd-clinical-trials-lectureship/>

- **We supported a Heart Study (Arrhythmias) 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 dystrophinopathy. Both atrial and ventricular arrhythmias were documented, and even longer episodes were asymptomatic or minimally symptomatic. Some patients were shown to have an increasing arrhythmia burden over time. Prolonged, comprehensive surveillance, made possible by the 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 be 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 than traditional steroids. 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-effectiveness of drugs in 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 9<sup>th</sup> 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 23<sup>rd</sup> 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').

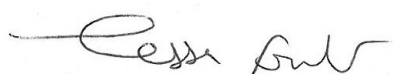
Having satisfied myself that the accounts of the charity are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). 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.



23<sup>rd</sup> 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

		Unrestrict ed funds	Total
	Not e	2022	2021
		£	£
<b>Income from:</b>			
Donations		<b>16,843</b>	28,979
Fund-raising activities		<b>206,169</b>	100,799
Bank interest received		<b>59</b>	10
Grants received		<b>2,809</b>	24,360
<b>Total income</b>		<b><u>225,880</u></b>	<b><u>154,148</u></b>
<b>Expenditure on:</b>			
Charitable activities	2	<b><u>(223,967)</u></b>	<u>(122,645)</u>
<b>Net income for the year/net movements in funds</b>		<b>1,913</b>	31,503
<b>Fund balances at 1 July 2021</b>		<b><u>140,163</u></b>	<u>108,660</u>
<b>Fund balances at 30 June 2022</b>		<b><u>142,076</u></b>	<u>140,163</u>

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 £
<b>Current assets</b>					
Debtors	3	12,925		17,222	
Cash at bank and in hand		<u>138,717</u>		<u>134,898</u>	
		<b>151,642</b>		152,120	
<b>Creditors:</b>					
Amounts falling due within one year	4	<u>(9,566)</u>		<u>(11,957)</u>	
<b>Net current assets</b>			<b>142,076</b>		140,163
<b>Total assets less current liabilities</b>			<b>142,076</b>		140,163
<b>Funds</b>					
Unrestricted funds	5		<b>142,076</b>		140,163
Restricted funds	5		<u>-</u>		<u>-</u>
<b>Total Funds</b>			<b>142,076</b>		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 23<sup>rd</sup> March 2023 and were signed on their behalf:

*E. Hallam*



## **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 remuneration 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**

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

## **3 Debtors**

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

**Notes** - continued  
(forming part of the unaudited financial statements)

**4 Creditors: amounts falling due within one year**

	<b>2022</b>	2021
	<b>£</b>	£
Income received in advance of events	<b><u>9,566</u></b>	<u>11,957</u>

**5 Movement in Funds**

	At 30 June 2021	Net movement in funds	At 30 June 2022
	£	£	£
Unrestricted funds	140,163	1,913	<b>142,076</b>
Restricted funds	-	-	-
<b>Total Funds</b>	<b><u>140,163</u></b>	<b><u>1,913</u></b>	<b><u>142,076</u></b>

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	-	-	-
<b>Total Funds</b>	<b><u>225,880</u></b>	<b><u>(222,649)</u></b>	<b><u>1,913</u></b>

**6 Employees:**

	<b>2022</b>	2021
Average number of employees during the year	<b><u>2</u></b>	<u>2</u>
Employment costs:		
	<b>2022</b>	2021
	<b>£</b>	£
Wages and salaries	<b>50,284</b>	43,873
Pension costs	<b><u>1,477</u></b>	<u>13</u>
	<b><u>51,761</u></b>	<u>45,189</u>

## Detailed Statement of Financial Activities

for the year ended 30 June 2022

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

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

**This page does not form part of the unaudited accounts.**