

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 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

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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 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.

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-RRIMhQmkhBhNylsS6hZA>
 - 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 steroids** - 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 news that the original trial had failed to meet both its primary and secondary endpoints and that all trials relating to this drug will be stopped. As a result, the funds 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 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 Neuromuscular 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 through [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 (Arrhythmias) 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 steroid-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 supporters 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



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

		Unrestricted funds	Total
	Note	2021 £	2020 £
<u>Income from:</u>			
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		<u>154,148</u>	<u>207,498</u>
<u>Expenditure on:</u>			
Charitable activities	2	<u>(122,645)</u>	<u>(157,755)</u>
Net income/(expenditure) for the year/net movements in funds		31,503	49,743
 Fund balances at 1 July 2020		 <u>108,660</u>	 <u>58,917</u>
 Fund balances at 30 June 2021		 <u>140,163</u>	 <u>108,660</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 2021

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

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:



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 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

	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	<u>7,451</u>	<u>15,877</u>
	<u>122,645</u>	<u>157,755</u>

3 Debtors

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

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	<u>11,957</u>	<u>3,694</u>

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	<u>108,660</u>	<u>31,503</u>	<u>140,163</u>

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	<u>154,148</u>	<u>(122,645)</u>	<u>31,503</u>

6 Employees:

	2021	2020
Average number of employees during the year	<u>2</u>	<u>1</u>
Employment costs:		
	2021	2020
	£	£
Wages and salaries	43,873	23,250
Pension costs	<u>1,316</u>	<u>698</u>
	<u>45,189</u>	<u>23,948</u>

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		<u>100,799</u>		<u>156,488</u>
Total incoming resources		129,778		201,178
RESOURCES EXPENDED				
Charitable activities				
Charitable event expenditure:				
<i>Big Xmas give</i>	164		-	
<i>Golf Day</i>	-		4,156	
<i>Coast to coast ride</i>	1,419		-	
<i>Tour de Alex</i>	72		-	
<i>Prudential Ride London</i>	560		-	
<i>Annual Fundraising Ball</i>	-		10,157	
<i>Masquerade Ball</i>	3,169		-	
<i>Ethical Business Club</i>	335		466	
<i>The Brothers Trust</i>	324		-	
<i>Super cars event</i>	270		-	
<i>Be More Alex regular giving campaign</i>	632		-	
<i>Art Exhibition event</i>	-		2,380	
<i>AGM/Supporters Thank You Lunch</i>	649		-	
<i>Kreative Group's Miss GB Finals Event</i>	-		70	
<i>Virtual 'Take That' Night</i>	-		120	
<i>Leicestershire Cricket Ground Fireworks Night</i>	-		817	
<i>Leicestershire Law Society Zipwire Challenge</i>	-		39	
<i>Other sundry event costs</i>	<u>72</u>		<u>72</u>	
		<u>(7,666)</u>		<u>(18,277)</u>
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	<u>2,356</u>		<u>2,440</u>	
		<u>(52,837)</u>		<u>(64,478)</u>
Bank interest received - gross		<u>10</u>		<u>126</u>
		69,285		118,549
Payments for research and clinical trials		<u>(62,142)</u>		<u>(75,000)</u>
Government grants received		<u>24,360</u>		<u>6,194</u>
Net incoming/(outgoing) resources		<u>31,503</u>		<u>49,743</u>

This page does not form part of the unaudited accounts.