



Alex's Wish

His wish,  OUR MISSION 

Help us conquer Duchenne

Alex is a 10 year old boy who was diagnosed with Duchenne Muscular Dystrophy in 2010. Duchenne is a very serious life-limiting muscle wasting disease and affects 1 in every 3,500 boys (it also affects girls but they only account for 1% of all diagnosed). It is the biggest genetic childhood killer condition and the most lethal and common form of Muscular Dystrophy.



Put simply Duchenne leaves boys in wheelchairs by their early teens and completely paralysed by late teens. Boys typically die in their early to late twenties of heart or respiratory complications.

There is no cure and currently no treatments available for Duchenne, which is why it is Alex's Wish to cure Duchenne. Our mission is to save lives and stop this devastation!

So what does this all mean for those affected...

Imagine a life where every moment becomes a struggle, you get up in the morning and need 24 hour care to help you get out of bed, wash and get ready. You need help to eat and are unable to scratch the itch you have on your nose. You require a respiratory machine to keep you alive and are unable to walk out of your front door, get in a car and drive to where you want to go.

For adults with Duchenne everyday life is a constant battle for a future they have little hope for. They see their friends with Duchenne die one by one leaving them feeling isolated and with the knowledge of what lies ahead for them. They live a life trapped in a body that doesn't want to work.

Boys like Alex also live with daily struggles too. They are unable to play sports as they are unable to keep up with their friends; they need a wheelchair as walking even a short distance is too difficult for them.

Duchenne also devastates the families of those affected, as they are often unable to cope with the diagnosis, as well as the care and support needed to bring up a child with Duchenne. Then, of course, there is the constant emotional turmoil of Duchenne's devastating and relentless destruction of the one they love.

These are just some of the reasons why we need to find a cure for Duchenne right now! Families have to live in hope. Your support and help will have a massive positive impact on those lives affected.

Our vision

Our vision is to witness a world without Duchenne Muscular Dystrophy. We want a future where the devastating impact Duchenne has on our children no longer exists; a future where they can grow and prosper and fulfil their dreams whilst not living trapped in their own bodies. A life where they can enjoy every day without fear of what Duchenne will bring.

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

Within the next 10 years we want to stop the devastating effects this condition has on the boys and young adults with Duchenne. We want to save their lives.

We will achieve this by working with the leading scientists from around the world to bring potential viable new life-saving drugs to market. We will work tirelessly with other UK and world-wide leading Duchenne charities to co-fund clinical trials and research projects and to work on clinical trial capacity issues to make our mission a reality in the years to come. With increased awareness and increased funding we'll extend and improve lives of all those affected by Duchenne.

Our values

- We are a small charity with a big heart
- We go the extra mile in making our supporters feel valued
- Positive, upbeat and committed totally to our sole aim
- We like to give as much support to the businesses who raise money for us through social media and PR coverage
- We are totally transparent

Our urgent need for funding

We need to provide substantial funding to several clinical trials and research projects over the next 3 to 5 years that will provide a catalyst to drive significant investment from biotech and pharmaceutical companies. We have a target of £1,000,000 raised and invested by 2020.

A significant factor in getting treatments out of the laboratory and into clinic is funding! Rare diseases get very little funding from the government so it is down to charities such as Alex's Wish to do it. It is likely multiple drugs and treatments will be needed to repair, restore or replace the missing protein in Duchenne called 'dystrophin'. This missing protein is what causes the disease.

Having met and spoken to some of the best organisations in the world fighting Duchenne it is clear that for the very first time there is likely to be a chance of **a major breakthrough**. This generation of children could be the ones to survive this condition – but only if action is taken now.

With only one treatment available Translarna which was given the green light by NICE in April 2016 will only treat around 13% of the Duchenne population, that's 50

boys in UK, we have to work hard to find more treatments that will treat ALL boys and not just a sub-set. However, with the first drug that treats the underlining effects of Duchenne, it is a huge step in the right direction.

Without funding, our vision will not happen. The need for funding is urgent because of the many opportunities that now exist. The research landscape for Duchenne has never been more prevalent; however, without urgent funding this work will not happen now, resulting in no new treatments for this generation. Our boys deserve a future they can look forward too and we must take action now!

Our History

Alex's Wish was founded in late 2012 by Emma and Andy Hallam, Alex's mum and dad, with the sole aim of eradicating Duchenne. With little charity experience they've grown the charity to what it is today with passion, enthusiasm and drive to help their vision become a reality.

Emma explains: "Once Alex was diagnosed we spent our first year grieving for the future we had now lost. But once we started to come to terms with it we knew we had to make a positive difference to the lives of those affected. Sitting back and doing nothing was not an option. We could not sit back and play the waiting game. Raising money was everything if we were to have any hope for a different future."

Within 3 years of launching Alex's Wish we have:

- Significantly increased our funds raised every year.
- Amassed a supporter database of over 1,000 individuals and businesses.
- Invested over £230,000 into promising new treatments and into increasing clinical trial capacity.

This year we are on target to raise £140,000 and we are currently reviewing a number of projects to fund over the coming months.

We have own scientific advisory board who evaluate proposals against strict success criteria. This ensures that our funds are only invested in the most promising projects and clinical trials that are both of high scientific quality and have a clear route to market within the next 5 years.

Alex's Wish has formed a partnership with the Muscular Dystrophy UK and 5 other charities dedicated to beating Duchenne. The collaboration is called the Duchenne Forum with a prime purpose of accelerating progress in the search for effective

treatments and eventually cures. The partnership has committed £840,000 over the next 4 years.



Our flagship events

We hold a number of flagship events throughout the year:

- **Charnwood Forest Cycle Ride**, this local community event attracts 200-300 cyclists each year ranging from amateur to experienced cyclists raising up to £10,000 for our cause.
- **Charity Golf Day**, this event attracts local businesses with up to 100 golfers attending the day providing a fabulous networking opportunity and raising in excess of £10,000 per year.
- **Dandelion Ball**, our fabulous black-tie evening attracts existing supporters and local businesses to use the opportunity to entertain employees and clients. This event attracts 250 guests and raises up to £35,000 per year.
- **London to Paris Cycle Ride**, a 3-day cycling event attracting up to 20 cyclists this event raises £35,000 for our cause.
- **Prudential Ride London**, a 100-mile bike ride on closed roads throughout London and out into the Surrey Countryside raises £30,000 per year.
- **Charity Sky Dives**, this event attracts many supporters and raises over £10,000 per year.
- **Ladies Pamper Evenings**, this event attracts local supporters and raises in excess of £2,000 per year.

Our future goals

Fundraising initiatives

The majority of our income to date has been raised through hosting our own events. We aim to work within a 30:70 ratio of cost to income to ensure that 70% of what we raise from our events overall goes directly to potential life-saving treatments.

Our aim for the future is to:

- Increase corporate sponsorship opportunities to cover our event costs.

- Increase fundraising initiatives that have a zero-cost attached to them by attracting Wish Warriors to raise funds through their own means.
- Introduce a 'Give you as Earn' scheme to increase regular giving.
- Maximise national events such as the worldwide Duchenne Awareness Day, Giving Tuesday and National Volunteers Week
- Forming strategic alliances and partnerships with organisations such as local sporting clubs, colleges and corporates

Grant applications

Alex's Wish has fixed costs totalling £21,800 per year. This includes a part-time event manager, accountancy and CRM systems, event insurances and networking event costs to help increase our profile and support in the local area. We will be applying for grants to help cover these costs. This will further help reduce our cost to income ratio. Our board of trustees and founders work on a voluntary basis. Our accountant and graphic designer also work on a voluntary basis.

Award winners

In 2016, Alex's Wish won the prestigious **Leicester Mercury Business Awards – Not-for-Profit Category** sponsored by PLUS interiors. The Leicester Mercury Business Awards aim to celebrate success, recognise achievement and highlight innovation in Leicestershire who are helping put the region on the map by boosting the economy whilst making a positive contribution to the local community.

Selected from 17 local charities, Alex's Wish was nominated as one of three finalists. In the final we were up against two large and well known charities The Rainbows Hospice and The Matt Hampson Foundation, we were thrilled to receive this award and shows our successes to date.



In 2015, Alex's Wish won the Niche Business Awards Courage award for achieving outstanding progress whilst doing exceptional work locally.



Our Wish Warriors

Our 'Wish Warriors' are our key supporters who take part in our events, help spread the word about our cause, take part and run their own events or simply make a donation.



As a small charity, we go out of our way to show we care. We are very committed to supporting our Wish Warriors so they have a great experience fundraising by going the 'extra mile' to make them realise how important their support is to our cause. This includes training days to meet up prior to a challenge, gift bags, and encouragement from Alex with regular video blogs, event jerseys, on-going communications and support from start to finish!

We also bring tangible benefits to people:

- We bring people together creating a local community.
- We encourage people to get involved in challenges they never thought possible as we provide opportunities to take part in life-changing events.

- We've made new friends and met other families going through the same journey as we are.
- We've now got a huge support network.

We are very proud of the feedback we receive from our events, here are a few examples:

Kenny Whomsley, Director at KK Installations, Leicestershire

“We've been supporting Alex's Wish since the charity was started in 2012. Alex's Wish was started by Emma & Andy due to their son Alex suffering from Duchenne Muscular Dystrophy. In a short space of time Alex's Wish has raised £350k and I know with the courage Emma has shown we will soon be near the target of £1m which has been set. Emma has been a true inspiration since starting the charity, working tirelessly to get businesses like myself to support the cause, I don't know where Emma gets the energy from, and all I do know is that Emma & the charity could/will conquer anything and with everyone's help the charity will go from strength to strength.”

Jessica Apps has raised £4k for Alex's Wish and is one of our key supporters

“I have been involved with the charity Alex's Wish for the last three years. I was at university with Alex's aunt and learnt through a mutual friend of Alex's diagnosis of Duchenne Muscular Dystrophy. My son is the same age, and it is the cruellest disease. I am in awe of how Alex's parents, Emma and Andy, have coped with the diagnosis, and the energy they have put into raising awareness of DMD and raising money for research by founding the charity Alex's Wish. Emma works tirelessly to manage and run many events, generating awareness and raising much needed funds – all this whilst still looking after Alex and his sister Isla. She is so positive and supportive and is an inspiration. Many of the big charities have large fund raising offices, but Emma always has the personal touch, and makes her supporters feel special. This year, my 2 children, husband and 2 friends took part in a 20 mile charity bike ride. We held a cake sale at school and raised around £300. The bike ride was a fantastic day with a wonderful, positive atmosphere. The best part for my children was getting to meet and play with Alex at the end of the ride, oh, and the cakes! Both the children received a personal certificate from Emma which they were very proud to take into school to show teachers and friends. On August the 2nd, my husband and I, and 2 close friends will be proud to take part in Ride London – a 100 mile bike ride – riding for Alex's Wish. We are immensely proud to support Alex's Wish, a local charity, who really is making a difference. “

Corporate Wish Warriors

We are always looking for support from local businesses and clubs such as The Masons, Rotary Clubs and Lions. There are many ways to get involved including:

- Choosing Alex's Wish as your Charity of the Year – one way to help raise funds is by running your own fundraising events, or perhaps allocating a % of sales income, whatever you decide on, we are on hand to help support with your ideas.
- A one off donation.
- Sponsoring one of our events.
- Donating prizes for our raffles and live and silent auctions.
- Displaying collection boxes and selling merchandise.
- Helping us raise awareness through your social media sites and website
- Help marshal at our events.
- Help promote our flagship events to your employees.
- Join in our 'Give as You Earn' scheme.
- Donate time and/or skills to our cause to ensure we continue to prosper and grow.

In exchange, we will work and support you and ensure it is a win: win relationship by promoting our relationship through local press, social media, and email newsletters to our supporter database and on our website. If you think your company or the company you work for could help, please get in touch with us, we'd love to speak with you about what impact you could have.

How we measure our success

It's important we measure ourselves against objectives set and do this in the following ways:

- We hold bi-monthly trustee meetings to discuss progress made and next steps.
- We hold monthly budgeting reviews – spend vs. income.
- We thoroughly review all events and agree how best to improve in the future.
- We place funding as quickly as possible rather than holding onto money.
- We set ourselves stretching annual objectives with clear plans on how to achieve them.
- We regularly review and met with other charities for inspiration and follow tried and tested practices.

Our team

Our team consists Emma and Andy Hallam (Founders), Zoe Edwards (Part-time Events Manager), Richard Amphlett, Trisha Braisby and Adam Flowers (Trustees)



How to contact us

Web: www.alexswish.co.uk

Watch our short video: <https://www.youtube.com/watch?v=VgQWsQUyNiw>

Facebook: www.facebook.com/alexswishcharity1

Twitter: www.twitter.com/alexswish

If you would like to get involved or have any questions, please do not hesitate to get in touch at emma@alexswish.co.uk or call 07903 349475.