



ALEX's WISH

cure Duchenne

YOUR
EVENT
PACK



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cure Duchenne

20 GRANITE WAY,
MOUNTSORREL,
LEICESTERSHIRE,
LE12 7TZ
CHARITY NO: 1148845

We are thrilled to hear that you have chosen to support Alex's Wish. Duchenne Muscular Dystrophy is a terrible condition to live with – lets help find a cure!

Alex is now 11 years old and whilst he's doing really well, we know this could change at any time – he is so grateful for all the work our supporters give to help bring about new treatments for all children living with this terrible condition.

When we set up Alex's Wish there was no cure or treatment for Duchenne. We knew that there were opportunities, but they lacked funding – alongside other parent led charities we have joined together to ensure that these opportunities become a reality.

You can rest assured that every pound you raise for Alex's Wish will go straight in to the hands of the world's leading scientists and researchers ensuring Alex's Wish of finding a cure will become a reality.

So Good Luck with your event, I can tell you first hand that supporters like you are invaluable to all boys and families with Duchenne.

Best wishes

Emma Hallam
Mum of Alex and Founder of Alex's Wish



BOOST YOUR FUNDRAISING

This guide will help you make your event as successful as possible, it will detail everything that you need to know to help you get the most out of your efforts.

SET A TARGET

Setting yourself a fundraising target is really helpful. Not only does it help you to stay motivated, but it can help boost the total that you raise. It also means that your supporters know how much you want to raise and they will help you get there. It is definitely worth considering, after all the more you raise the bigger your impact for all boys with Duchenne.

PUBLICITY AND PR

Promoting your fundraising activity through the media will help you shout about your efforts and ultimately raise more money for Alex's Wish. You could obtain excellent publicity in your local media – newspapers, local magazines, radio or even TV stations. You can find your local newspaper and magazine contacts in their publications or online. Remember it's always worth following them up with a phone call.

If you have a Facebook page, or if you are on Twitter or Instagram, make sure that you tell your friends and followers all about your fabulous fundraising efforts. Social Media is a great way to keep everyone updated. We would love you to share your amazing fundraising ideas and efforts with us too on our social media channels.



FACEBOOK...

www.facebook.com/alexswishcharity1



TWITTER...

www.twitter.com/alexswish



INSTAGRAM...

<https://www.instagram.com/alexswish/>

ONLINE DONATIONS

You can make it easier for people to support you and donate funds by setting up a BT Donate page where you can collect donations from all your family, friends and supporters online. Saving you from paper sponsorship and the time taken to collect donations in.

It is incredibly simple to set up a BT Donate page for your event – simply go to <https://mydonate.bt.com/charities/alexswish> and select 'Create a Fundraising Page'

Once you have done that (including setting a total and adding an image) share that link to all your supporters so they can see how you are doing.

Why not add your link to the bottom of your email signature to reach out to people every time you send an email. Be sure to promote your page after you have completed your event. Often people will sponsor you when they have proof you have completed it. Be sure to thank all your supporters after the event.

GIFT AID

We love Gift Aid here at Alex's Wish, that is because every £1 that is donated to you by your supporters (provided that they are paying tax at the time of the donation) HMRC will give us an extra 25p at absolutely no cost to your supporter. So to increase all your donations by 25% make sure all your supporters use Gift Aid on their Donation. If everyone manages to increase their donations this way it will mean even more money goes straight towards finding treatments to help this generation of boys with Duchenne.

PROMOTIONAL MATERIALS

We have a range of materials available for our supporters including wristbands, t-shirts, running and cycling tops, collection boxes and leaflets. We can also provide you with a personalised poster, social media images, press releases, standardised letters to approach local businesses for support all of which may prove really useful to you in getting your event out there. Get in touch with zoe@alexswish.co.uk and we will support you every step of the way.



DOWNLOAD OUR APP USING THE QR CODE...

<http://wsu.ma/alexswish>



TOP TIPS TO TOP UP YOUR TOTAL

PRE-SALES

If you are doing a ticketed event, make sure that you sell tickets ahead of the event, that way you will get the money even if the person decides not to come along. Also by selling tickets up front it will help you manage your event more efficiently as you will not over cater.

GET YOUR BUSINESS ON BOARD

Ask the business that you work for to support you either by making a donation or holding an event for employees like a cake sale or a dress down day. Some larger companies will also offer 'match-funding' to their employees, so it is always a good idea to ask if your company does this. For more ideas get in touch.



RAFFLES AND AUCTIONS

Raffles and Auctions are always a good idea to boost fundraising at events. Do not worry about going out and getting hundreds of prizes – people will buy raffle tickets anyway. Raffles are strictly regulated so you will only be able to sell tickets at the event itself. If you are struggling to get prizes you can always allocate some of the raffle takings to be the prize. If you do decide to do an auction it is always a good idea to talk about Alex's Wish and the difference that the donations will make, that way they may dig a little deeper in to their pockets.

You have spent lots of time planning your fantastic event and you can't wait to start raising lots of funds – here are some top ways that you can maximise your fundraising that are guaranteed to get all your supporters digging deep.

SPONSORSHIP

If your event is open to the public, consider approaching local businesses to sponsor you. In return for their donation you can offer to put their logo on any printed materials for your event i.e. tickets and posters, as well as any of their marketing materials being displayed at the event itself.



TELL YOUR STORY

If you are doing a personal challenge, consider doing a blog or documenting your experience through social media. You could build up quite a following and an increase in donations. Create videos of your training and upload it to YouTube, then share your links. Ask your friends and family to share your posts.



KEEP IT LEGAL AND SAFE

At Alex's Wish we like to bring the Fun back to Fundraising, and we fully encourage you to do the same. However, like everything it is subject to laws and legislation. Here are a few things that you should consider.

COLLECTIONS

Collections are a great way to raise money, especially in a busy area. However if you are planning a collection that takes place in a public place then this is governed by strict legal laws and must be licenced by your local authority. If you would like to do a collection in a privately owned venue such as a shopping mall or a pub you must ask the owners permission beforehand. We do not endorse house to house collections by our supporters.

RAFFLES AND LOTTERIES

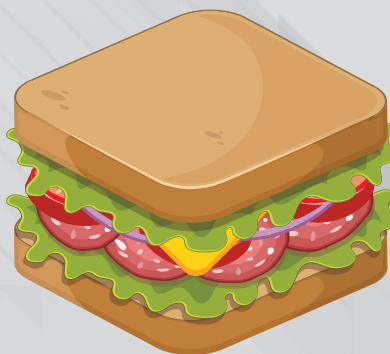
Raffles, Lotteries and prize draws are all governed by strict regulations. So if you want to hold one, please get in touch with us so we can make sure that you stay this side of the law. Also, be aware that lottery laws cover any events which are purely down to luck or chance, such as Duck and Balloon races.

DATA PROTECTION

Make sure that any electronic or paper records you keep about people involved in your event comply with the Data Protection Act. To simplify don't keep information about people longer that you need to and don't share that information about someone without their permission.

INSURANCE

When you organise an event, you are responsible that it will not cause a risk to others. That is why we'd recommend that you take out public liability cover for big events like a sponsored walk or sports day. Unfortunately our insurance will not cover you – if you need advice please do get in touch with us.



FOOD HYGIENE AND ALCOHOL LICENCE

Please take care when handling food and please work to basic food hygiene standards – you don't want anyone going home from the event with a tummy ache! If you are selling alcohol at your event and the event location does not have a license you are able to apply for a personal license for the actual event itself from your local authority.

If there is anything that you are unsure of or you would like further information, please do not hesitate in getting in touch.



CASESTUDY

ELAIN CREWE WALKING CHALLENGE

Our fabulous supporter **ELAIN CREWE** from Wellbeing4Life organises a 'Challenge' walk each year for her Boot Campers raising money for Alex's Wish

The first year Elain arranged for a group to take part in the Yorkshire Three Peaks and managed to raise £3,600. The following year Elain arranged a bespoke route around Ullswater. It was a 30 miles (plan was 25 but turned out to be further!) trek over 3 peaks as well as undulating ground through forests, around the beautiful Ullswater lake totalling 1,400m of ascents. The trek is part of the Ullswater way, but with additional challenges. The second

year Elain doubled her fundraising total to £7,163.25. "I have a 14 year old son myself and when I heard Emma speak at an event I couldn't help but be touched by Alex's story and the passion with which Emma and her family and friends fight every day for a cure to this hideous disease. I consider myself truly blessed to have a healthy son who is able to participate in sports and other activities that all young boys should be able to do and I wanted to do anything I could to try and support the cause. My business is about supporting local people to be their best selves through healthy living and it was important to me to support a local charity.

At Wellbeing4Life we run an annual fund raising event in the shape of a trek in a different part of the country each year. So far we have done the Yorkshire 3 Peaks and Ullswater. In 2018 it will be Derbyshire. The trek is undertaken by my amazing boot camp clients; they do it for the personal challenge but I absolutely know that the motivation to keep them training and to keep them moving when they're exhausted is that we do this for Alex's Wish. It adds something extra special to their experience knowing they also raise money for this amazing local cause."



CASESTUDY

OUR FAB SUPPORTER JESSICA APPS

Now this is a tale about one of our amazing Wish Warriors, her name is **JESSICA APPS**. Jessica for years had tried to fall in love with running, and finally about 2 years ago it started to click. Jessica said that her inspiration started when she worked on the Olympics project and started running weekly Park Runs. Jessica started to lose weight and began to feel healthier, and so her running really started to improve. Then Jessica ran her first half marathon, with a broken toe, she was so determined to complete it.

When Jessica celebrated her 40th birthday, her daughter suggested that she should do 40 park runs. To make it even harder Jessica decided to do 40 different sporting events, these included park runs, open water swims,

triathlons, 50 mile bike ride, half marathons and the Prudential Ride London (which she completed with her friends Rebecca and Suzy), and even better for us Jessica decided to do all these events whilst raising money for Alex's Wish.

Over the year Jessica managed to complete all 40 events, the last one being a Halloween Fun Run, and has managed to raise a staggering £3,396.80 for Alex's Wish. Without Wish Warriors like Jessica we would not be able to raise the funds that we do, to help fund treatments and potential cures for this devastating disease, so thank you Jessica for choosing to support Alex's Wish - you are a true Wish Warrior.



WHERE YOUR DONATIONS GO

Thanks to supporters like you, Alex's Wish can help accelerate the time taken to get potential treatments to market, meaning less families will have to experience the devastating effects of Duchenne.

The figures to the right show what the money you raise could fund. If you would like to set a target and be able to quote a project that you would be making an impact with – please get in touch and we can give you all that information.

HOW YOUR MONEY MAKES A DIFFERENCE...

£50
PAYS FOR
scientific equipment
for a day for
crucial testing

£200
PAYS FOR
a post doctoral
researcher for a day to
work on innovative
new treatments

£800
PAYS FOR
essential pre-clinical
work per year to prove the
effectiveness and safety of
new treatments to move
them into clinical trial

IT'S EASY TO PAY YOUR MONEY IN

Please follow these guidelines for the different ways you can pay in the money you have raised or donated to Alex's Wish.



BANK TRANSFER

The easiest way to pay in your fundraising is directly in to the Alex's Wish Bank Account:

Bank: NatWest
Sortcode: 54-21-50
Account No: 30282950



POP IT IN THE POST

Or send a cheque made payable to 'Alex's Wish' and your sponsorship form to:

**20 Granite Way,
Mountsorrel,
Leicestershire, LE12 7TZ**
Please do not send Cash



PAY ONLINE

You can pay your money in directly to us via our donate button on our website...

www.alexswish.co.uk



SPONSOR FORM

EVENT TITLE:

EVENT DATE:

Don't forget to tick the gift aid box and quote a postcode. It doesn't cost you any extra but allows Alex's Wish to reclaim the tax on your donation. Thank you.

We can claim Gift Aid tax relief of 25p on every pound you give. To qualify for Gift Aid, what you pay in income tax or capital gains tax must at least equal the amount that the charity will reclaim on the donation. Please send the completed form to Alex's Wish to enable us to claim back the Gift Aid

[illegible]



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DONATIONS FORM

Please use this form to donate money raised from Your Event.
Complete and send in with your sponsor form(s):

NAME:

ADDRESS:

.....

.....

TEL:

MOBILE:

EMAIL:

MY BT DONATE PAGE IS (if applicable)

.....

We would like to add you to our newsletter database so that we can keep you up to date with information about our events, funding updates and other ways you can help. We promise to keep your details safe and we will never sell or swap your details. And if you change your mind about hearing from us you can stop receiving our updates at any time by emailing zoe@alexswish.co.uk.

Please do contact me by email

☐

Please note: Any funds you raise via BT Donate will automatically be paid into the Alex's Wish bank account. If you have set-up a BT Donate page and you are sending in money via the printed sponsorship form, we will send you a certificate of thanks totalling the whole amount raised.

Please return this form with your gift to:

Alex's Wish,
20 Granite Way, Mountsorrel,
Leicestershire, LE12 7TZ

giftaid it

**THANK YOU FOR MAKING A DIFFERENCE
TO BOYS WITH DUCHENNE.**

THANK YOU SO MUCH FOR RAISING FUNDS FOR ALEX'S WISH.

If you have any questions about your activity, we are here to help. Get in touch at zoe@alexswish.co.uk

THE TYPICAL TIMELINE EXPECTED FOR BOYS WHO HAVE DUCHENNE

3-5

Boys are typically diagnosed around 3-5 years old.

3-7

Early years (3-7) boys will start to struggle on their feet, find it difficult to climb stairs and are weaker than their peers.

7-12

Around the age of 7-12 years, boys will typically require a wheelchair to get around and will have to attend lots of hospital appointments to check on heart and lung health, bone density and regular physiotherapy appointments.

13-19

Around the age of 13-19 years old boys may show signs of a curving spine due to the amount of time they spend in a wheelchair and will require corrective surgery. Families are likely to need to give up their jobs to care for their child around the clock.

20-25

Around the age of 20-25 years old young men are likely to need a respiratory machine and heart medication to stay alive as they are unable to breath on their own and have difficulty swallowing food.

mid-20s

By mid-twenties, they will often need a feeding tube to keep them alive and most young men will lose their battle before the age of 30 years old.

The impact this condition has on families is immense – in terms of emotional wellbeing and the sheer amount of ongoing care they need to give. Often families are unable to travel leaving them trapped inside their homes. It's a truly devastating disease affecting children and young men.

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Alex's Wish. Registered Charity Number: 1148845. Registered address; 20 Granite Way, Mountsorrel, Leicestershire, LE12 7TZ