



IMPACT REPORT

2019



Two families a week in the UK are told that their child has Duchenne muscular dystrophy (DMD), a devastating muscle wasting disease that mainly affects boys.

Duchenne UK is an ambitious and highly focused charity, investing millions of pounds in research right now to bring treatments and a cure and to help this generation.

JOIN US TO END DUCHENNE

What is Duchenne muscular dystrophy?

Duchenne Muscular Dystrophy (DMD) is a devastating muscle wasting disease and is the most common fatal genetic disease diagnosed in childhood.

Children born with Duchenne muscular dystrophy have a fault, known as a mutation, on their dystrophin gene, the longest gene in the body. The fault means that they cannot produce dystrophin, a protein that is vital for muscle strength and function. This lack of dystrophin results in a progressive deterioration of muscle strength and function.

The disease almost always affects boys, and they tend to be diagnosed before the age of 5. It is classified as a rare disease with around 2,500 people

affected in the UK and an estimated 300,000 worldwide.

There is currently no treatments or cure, but thanks to recent breakthroughs, we believe we can save them.

What are we doing about it?

We are committed to continuing to drive momentum to deliver treatments to help THIS generation of those with DMD.

We have invested millions 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 DMD.

We have an innovative approach to funding. Not only do we fund basic research, but we fund clinical trials. We fund the doctors and nurses in the



UK to deliver those trials: and we look at where ever possible we can accelerate research and work with industry and regulators to get drugs approved.

Please read through our report to find out how we are making an impact in every area we possibly can to find treatments and a cure for DMD.

We have a growing army of supporters, without which none of this would be possible, so thank you to you all.



Duchess of Cornwall

Duchenne UK is pleased to announce that Her Royal Highness The Duchess of Cornwall will be the President of Duchenne UK for a further 5 years.

HRH The Duchess of Cornwall has been president of the charity (formerly Duchenne Children's Trust) since 2014.

Emily Crossley & Alex Johnson, co-founders of Duchenne UK, said:

“ We are extremely grateful to HRH The Duchess of Cornwall for her continued support of the charity. Her involvement right from the early days has been immensely important and we would like to thank her for everything she has done to help us and our community. ”



LETTER FROM CO-FOUNDERS, EMILY CROSSLEY AND ALEX JOHNSON

Thank you for reading our Impact Report – and we're so thrilled to share with you the progresses we've made this year.

Funding research is the beating heart of what Duchenne UK does. It's why the charity was set up. To offer real and tangible advances, and turn hope to reality. To push passionately for treatments, and to use our money and our advocacy to work creatively and with ambition to overcome the challenges in our way. We're working hard to develop drugs to treat and to end Duchenne. Our funding has led to clinical trials being run right now; with boys testing promising new medicines as we speak.

We invested £2.7million in doctors and nurses to run the trials in the UK and now more than 250 boys are on clinical trials in the UK who otherwise wouldn't be.

And we're also working hard to support people living with the condition by improving current treatments by looking at things like the use of testosterone; and investing in technologies that could have a profound impact on the quality of life of boys with DMD.

And we're nearing the end of the first phase of Project HERCULES, a truly ground-breaking and award-winning global collaboration to accelerate access to treatments.

There is so much to read in this year's Impact Report.

Since forming in 2016, Alex and I, with your support, have been proud to grow from a tiny patient organisation to a multi-million pound catalyser and funder of research bringing treatments and hope to this generation.

And what it comes down to is actually something parents are very good at. Resilience.

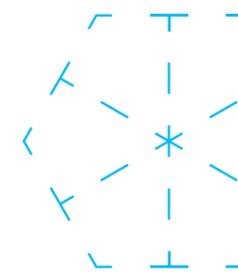
Resilience to survive those early years of parenthood. Resilience to survive those sleepless nights. The resilience to leave your child at nursery for that very first morning. And the resilience, when you are told that your child has Duchenne Muscular Dystrophy, to say NO. I will not accept that. I will not give into this.

This disease stole from us the luxury of choice - and left in its wake a gaping chasm of grief and despair. But it couldn't steal our hope. It couldn't - and it won't - steal our fight.

Thank you for helping us and for giving us the support and ammunition to keep on fighting.

Emily & Alex

Emily Crossley and Alex Johnson
Co-founders of Duchenne UK



CONTENTS

6 FUNDING RESEARCH

- 7 Tamoxifen
- 8 Recipients of our Major Grant Call
- 10 Evox
- 11 Gene Therapy
- 12 Testosterone
- 13 Taurine & Tempol

14 ACCELERATING ACCESS TO TREATMENTS

- 14 DMD Hub
- 16 Hercules
- 18 Early Access to Medicines

20 TECH

- 20 Whizz-Kidz
- 21 Solid Suit & Actimyo

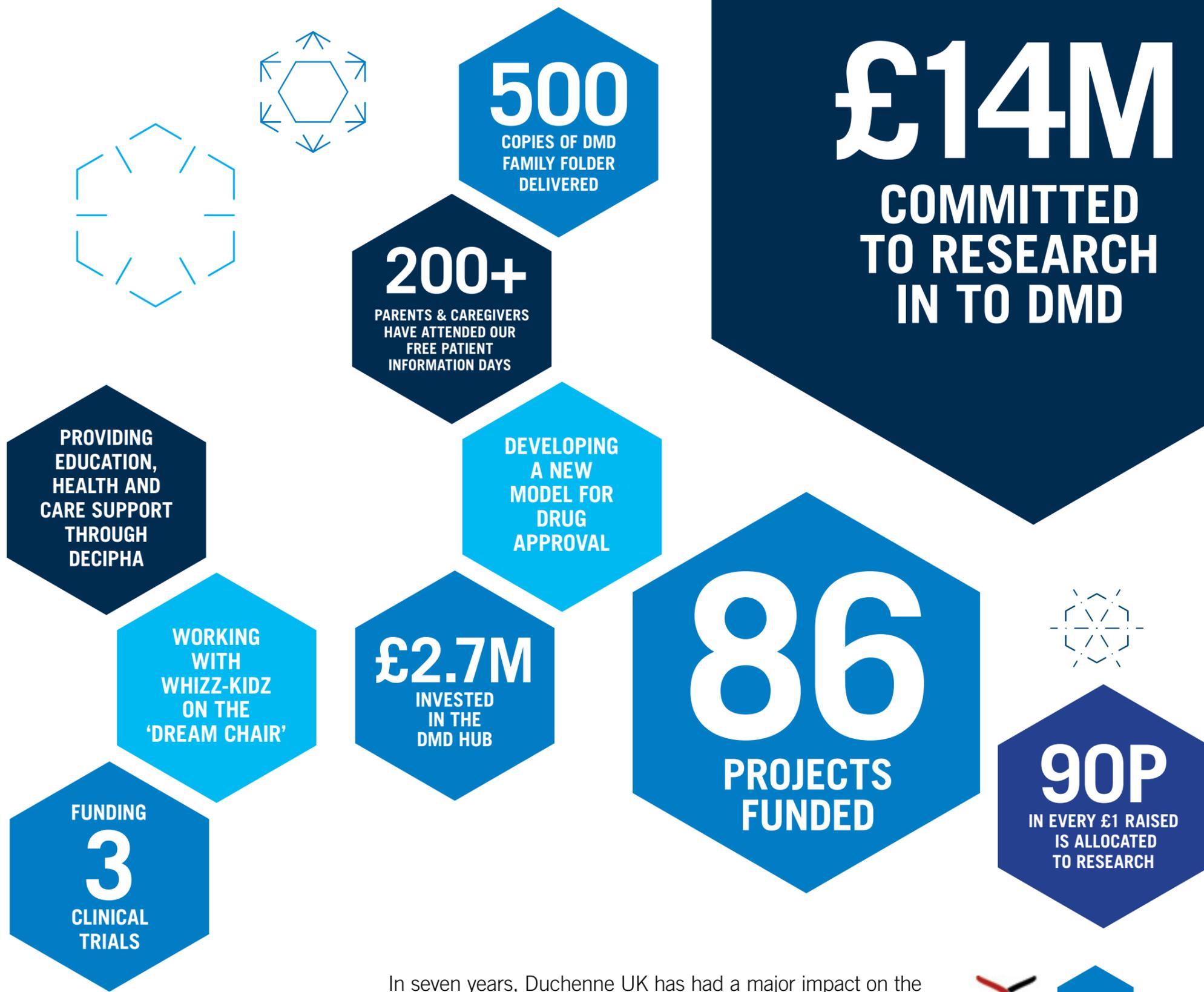
22 SUPPORTING PATIENTS

- 22 Patient Information Days
- 24 DMD Hub Website
- 25 DMD Family Folder
- 26 Decipha
- 27 Neuromuscular Complex Care Centre & DMD

28 SUPPORTING US

- 28 The Duchenne Dash
- 30 Family Funds
- 31 Partner Charities
- 32 Corporate Support
- 33 Saracens

35 PROJECT EXPENDITURE



In seven years, Duchenne UK has had a major impact on the DMD field, using an innovative, evidence based and results driven approach to accelerate the search for treatments and addressing many of the challenges in drug development.



Note: These overall spend figures reflect the combined spend of Duchenne UK and its charity partner Joining Jack. From 2012 – 2016, Duchenne UK operated under the name of Duchenne Children's Trust.

Funding research is the beating heart of Duchenne UK. It's why the charity was set up. To offer real and tangible hope where there hasn't been any before. To push passionately for treatments for this generation of children.

We don't take no for an answer. We work creatively, looking at both the detail and the broader picture of potential treatments and consequently we are succeeding in ways no other charity has done before.

TAMOXIFEN

Our first fully funded trial

We are delighted to have played an integral part in setting up a trial repurposing the breast cancer drug, Tamoxifen, to see if it will reduce fibrosis, strengthen muscle tissues and delay disease progression — following successful trials in mice.

As well as investing more than one and a half million pounds to make the trial happen, we have been helping

to recruit people with DMD to take part though the DMD Hub.

More than 30 patients have already been dosed.

This trial would not have happened without our support and we are confident it has the potential to make a real difference to DMD patients.

Emily Crossley & Alex Johnson, CEOs and Co-founders of Duchenne UK said:

“ This trial would not be happening in the UK if it wasn't for the funding and commitment of Duchenne UK. We would like to thank the teams at Leeds, Alder Hey and Glasgow for their commitment to opening as trial sites. We would also very much like to thank the boys and their families who will take part in the trial. ”

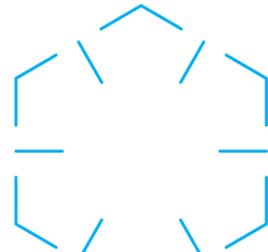
Professor Dirk Fischer, from UKBB, the University Children's Hospital in Basel, Switzerland in Switzerland who is running the study, said:

“ Duchenne UK and the other patient organisations came in with funding at a very critical moment. Despite a positive evaluation and a recommendation by the E-Rare review process, this trial would not have been possible at all without the co-funding from Duchenne UK and the other patient organisations. I am extremely grateful for their ongoing support, which has included not only financial help, but also help negotiating with regulatory authorities and other involved parties. ”



**£1.5M
COMMITTED**

**30+
PATIENTS
DOSED WITH
TAMOXIFEN**



RECIPIENTS OF OUR MAJOR GRANT CALL

Inspiring new treatments

We reached out to the research community this year, offering them 1 and a quarter million pounds in funding if they could present us with projects that would benefit DMD sufferers.

We were delighted by the response, and — after careful consideration — selected four groups which we felt offered sound methodology, investigating key issues.

The four projects look at different ways to build new muscle, tackle fibrosis and regenerate muscle. All are focussed on bringing new treatments to patients in as short a time frame as possible.

We are excited to say that, in addition to these four projects, we are now funding more than 60 projects worldwide.



£1.25M
MILLION COMMITTED

Our four DMD MAJOR GRANT CALL recipients were:

DMDINSPIRE

2019 MAJOR GRANT CALL

£780,000

University of Minnesota

An investigation into the use of stem cells to regenerate muscles.



£235,000

AGADA Biosciences

A study of whether two approved drugs, Tofacitinib and Ruxolitinib can protect muscles.



£199,245

University of Geneva

Research into repurposing already approved compounds like montelukast and tamoxifen can prevent fibrosis and regenerate muscle.



£73,500

Leiden University

A project looking in to the potential of use Vitamin B3 to improve regeneration of muscle and help retain muscle tissue.



EVOX

Enhancing potential gene therapy treatments for DMD

Several companies are trying to use a synthetic gene to replace the faulty dystrophin gene in Duchenne to create micro-dystrophin. This gene therapy replacement could turn on the production of dystrophin in the body - countering the effects of DMD. They are using viruses to deliver the gene around the body, but this is proving challenging as many people carry anti-bodies against these viruses. Duchenne UK has invested £655,000 in investigating whether exosomes, which occur naturally in the body,

can be used instead of a virus to carry micro-dystrophin around the body. Exosomes are nanometre-sized vesicles 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. The aim of this project is to see if we can use these exosomes to deliver gene therapy to muscle cells without the potential of the serious immune side effects associated with viruses.

£665K
COMMITTED

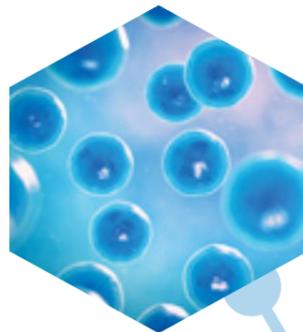


GENE THERAPY

Bringing Gene therapy trial to the UK

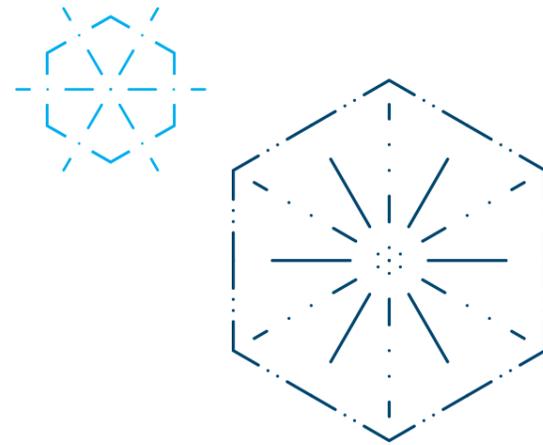
In 2014, Duchenne UK partnered with the Duchenne Research Fund and Joining Jack to commit \$5million to help fund pre-clinical work for Solid Biosciences' gene therapy programme. Solid Biosciences' are now running the clinical trial on boys with DMD in the USA. Sarepta Therapeutics and Pfizer are also running gene therapy clinical trials in the USA.

We are committed to bringing gene therapy trials to the UK as quickly as we can. So in November 2019 we hosted a meeting in Newcastle to discuss bringing gene therapy trials to the UK. The meeting was attended by more than 100 people including representatives from NICE, the NHS, UK hospitals and the pharmaceutical industry.



WATCH OUR FILM

Scan the QR code below with your phone camera to watch our film about Gene Therapy and Evox



TESTOSTERONE

Improving well-being for teenagers

Boys on steroids — currently the standard of care suggested for patients with DMD — have a delayed puberty. This is hard on a child, further isolating them and impacting on their mental health and well-being.

We have invested more than £228,000 into a research project looking at giving boys testosterone to bring on puberty, and how it impacts their health. To date, 15 adolescents have been dosed at the John Walton Muscular Dystrophy Research Centre in Newcastle.



LISTEN TO OUR PODCAST



Search "Decoding Duchenne" in your podcast app to listen to our special episode about the Testosterone project with Prof Volker Straub



TAURINE

Examining the benefits of supplements

Taurine is an amino acid which can be used as a health food supplement. Strong pre-clinical data in DMD mice suggests it improves muscle strength, reduces inflammation and protects against muscle wasting.

Duchenne UK has invested £273,648 for the University of Western Australia to investigate it as a potential treatment for DMD.



TEMPOL

Protecting muscle with new anti-oxidant drug

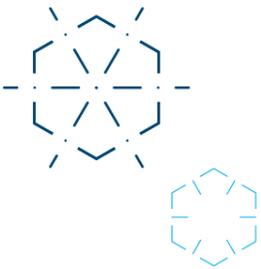
As part of Duchenne UK's commitment to accelerate the search for treatments, we are investing in the development of a new anti-oxidant drug that could potentially help protect muscle, with a grant to the University of Reading of £63,618.



ACCELERATING ACCESS
TO TREATMENTS

DMD HUB

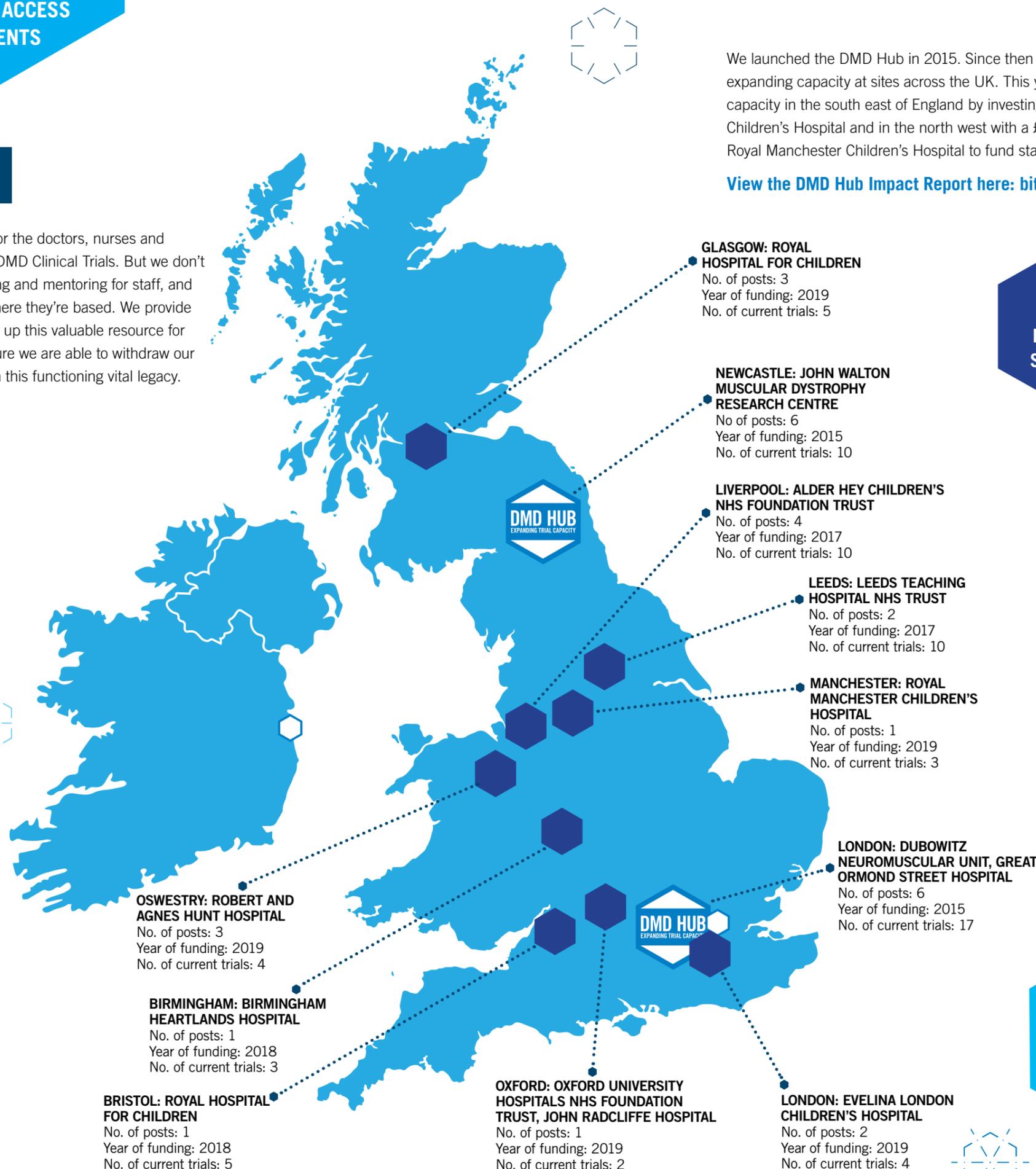
The DMD Hub funds posts for the doctors, nurses and support staff needed to run DMD Clinical Trials. But we don't stop there. We provide training and mentoring for staff, and resources to the hospitals where they're based. We provide the skills and expertise to set up this valuable resource for the NHS, and when it is secure we are able to withdraw our funding leaving the NHS with this functioning vital legacy.



DMD Hub Sites

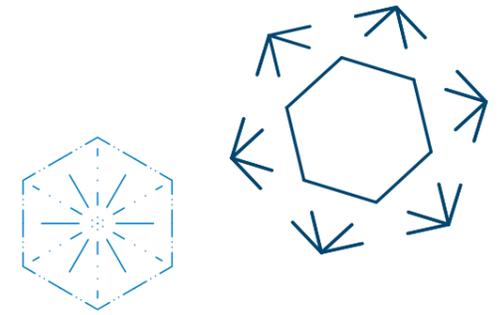
KEY:	
	Centres of Excellence London-GOSH Newcastle
	Hub site Alder Hey Birmingham Bristol Glasgow Leeds London - Evelina Manchester Oxford Oswestry
	Other sites Queens Square Temple Street

*No of current trials data as of October 2019



We launched the DMD Hub in 2015. Since then we have been tirelessly expanding capacity at sites across the UK. This year we increased capacity in the south east of England by investing £193,00 in the Evelina Children's Hospital and in the north west with a £130,00 grant to the Royal Manchester Children's Hospital to fund staff to help run trials.

View the DMD Hub Impact Report here: bit.ly/dmdhub2019



250+ PATIENTS RECRUITED SINCE 2015

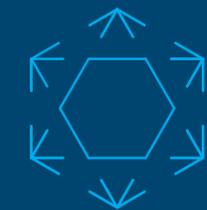
30 POSTS FUNDED

COLLABORATING WITH OTHER PATIENT ORGANISATIONS

9 ADDITIONAL DMD HUB SITES

£2.7M INVESTED

WORKING WITH THE UK CENTRES OF EXCELLENCE, NEWCASTLE AND GOSH





THE AWARD WINNING PROJECT HERCULES

This year Duchenne UK was awarded the prestigious EURORDIS Black Pearl Award in recognition of its innovative approach bringing together rival drug companies and health organisations to speed up the process of getting effective medicines to patients. Its aim is to help provide the data needed to support applications for funding of new drugs by bodies like the National Institute for Clinical Excellence.

for a rare disease, like Duchenne Muscular Dystrophy, and that has led to disappointing delays in reimbursement decisions. Project Hercules is creating the necessary tools to support pharmaceutical companies and help reimbursement decision-makers so that when a new treatment becomes available, there will be fewer delays in getting it to patients.

The eight pharmaceutical partners for the project are:

- Pfizer Inc
- Catabasis Pharmaceuticals Inc
- PTC Therapeutics International Ltd
- Roche
- Sarepta Therapeutics, Inc
- Solid Biosciences
- Santhera Pharmaceuticals Holding AG
- Wave Life Sciences USA, Inc



The inspiration for HERCULES

Duchenne UK recognised that in order for drug companies to get new treatments reimbursed by assessment authorities, there must be clear-cut evidence of the benefits of the drugs - showing how they improve the quality of patients' lives. In the past, there has been limited data available to provide evidence of drug effectiveness



HERCULES.

DMD: HEALTH RESEARCH COLLABORATION UNITED IN LEADING EVIDENCE SYNTHESIS



Recipients of the 2019 EURORDIS
Black Pearl Award:
Company Award for Patient
Engagement

Professor Alan Brennan Professor of Health Economics and Decision Modelling had to say:

“ The work you are doing is inspiring ... the commitment and the whole style of the approach is unusual, impressive and beautiful. ”



Emily Crossley presenting about Project HERCULES at the NICE Conference



ACCELERATING ACCESS
TO TREATMENTS



EARLY ACCESS TO MEDICINES

Changing the law to speed up access to new drugs

We were furious and frustrated to discover that while some potentially breakthrough drugs were ready to be used, they sat on the shelves for years because of licensing red tape. We are fighting for our children's lives and will not let red tape choke their chances. When we locate problems at any stage of the drug development process we are undaunted and drive through change. So we campaigned hard to change this — and in 2014 we won a change in the law to allow patients with life limiting conditions to access drugs which don't have marketing authorisation but which address a clear unmet medical need. This is the Early Access To Medicines Scheme (EAMS). We are very proud of our achievements through EAMS.

Vamorolone

This is a potential alternative to glucocorticoid steroids — but with fewer potential side effects. Duchenne UK, along with Joining Jack, and The Duchenne Research Fund, made a grant of \$1million to support its Phase 1 trial. We are delighted to say that this year the drug has been designated as a Promising Innovative Medicine (PIM) for treatment in Duchenne muscular dystrophy. This is the initial step towards access to the drug on the Early Access to Medicines Scheme

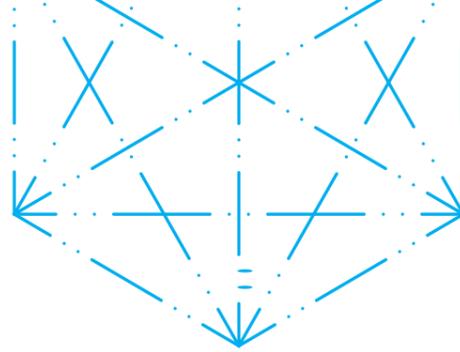
Raxone

Due to our lobbying for the EAM scheme, a drug which improves lung function RAXONE has now been given to 74 patients.



Our ambition is that everyone in the UK diagnosed with DMD is given the opportunity to take part in research





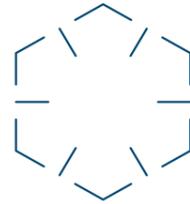
WHIZZ KIDS

DUK leads a wheelchair revolution

Duchenne UK recognises that for a person who can no longer use their legs, a wheelchair is not just a piece of equipment, it is an extension of their body and mind. It is key to accessing what every able bodied person takes for granted. But this vital piece of technology has changed little over the years. And Duchenne UK believes that the next generation of wheelchairs must be different, helping people achieve their full potential rather than burdening

them with logistical difficulties. That's why we are working with Whizz-kidz and the University of Edinburgh to improve current technology and designs, to revolutionise mobility equipment.

Last year, we partnered with Whizz-Kidz and the University of Edinburgh to win £1 million from the People's Postcode Lottery Dream Fund to develop a dream chair for wheelchair users.



DREAM WHEELCHAIR
COMPETITION
WINNER
ANNOUNCED



SOLID SUIT

Harnessing military technology to create wearable support for DMD 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.

Duchenne UK has contributed \$200,000 dollars to the project. We'd like to thank our partner charities - Alex's Wish, Duchenne Now, Joining Jack - and the Family Funds - Caring for Connor, Help Harry and Team Felix for their support.

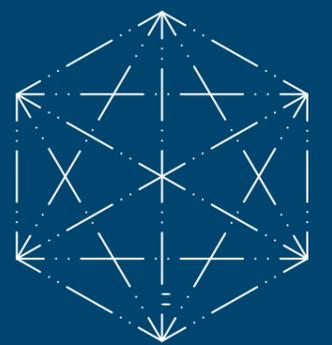
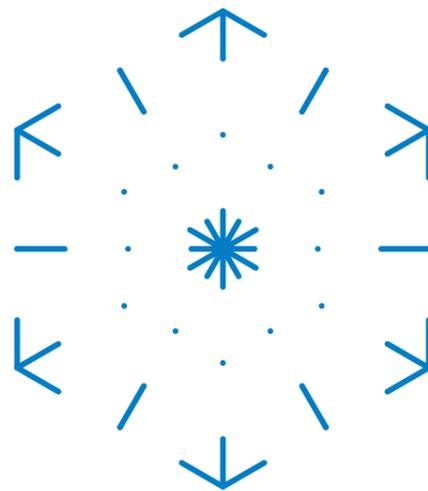
ACTIMYO

Wearable device get regulatory approval

ActiMyo is a device which has been developed to evaluate the physical condition of patients suffering with movement disorders. ActiMyo records the movements of a patient over the course of the day, in their usual environment, using a wearable device.

A new endpoint which aims to quantify a patient's ambulation directly,

reliably and continuously in a home environment with a wearable device is the first of its kind to be approved by the European Regulatory Authority for DMD. The regulatory work, critical to this outcome, was exclusively supported by Duchenne UK.



A diagnosis of Duchenne is shocking, isolating, bewildering. Duchenne UK is run by parents for parents. We know how you feel, because we have been there too. A key element of the charity is to support families. There are a number of ways we do this.

PATIENT INFORMATION DAYS

Empowering parents

When you're fighting to save your child's life, education is your best weapon - especially about access to new medicines - so that's why we hold free Patient Information Days. This year we welcomed hundreds of people to events in Manchester and London. We brought together experts in the fields of gene therapy, patient care and drug development. Guests included representatives from the drugs company Sarepta, the life science firm specialising in Duchenne - Solid Biosciences, the John Walton Muscular Dystrophy Research Centre, Royal Manchester Children's Hospital and Glasgow's Royal Hospital for Children. Andy Burnham, Mayor of Greater Manchester, kindly came to our day in Manchester and pledged to keep supporting the charity's efforts to accelerate research.

Many things swirl around the internet, promising much and delivering little. We are here to help you cut through the noise, to find the truth and fight for the best future for your children.

Quotes from attendees:

“ I came here to learn about the latest research about DMD, and not only did I get that, I learned about entrepreneurship, passion and making an impact. This is a different type of charity! ”

“ Excellent day! Lots of useful information and networking. I felt I was not on my own. I feel part of the Duchenne community. ”

“ Great information day - that's exactly what we got. Lots of positivity, practical help, advice and discussions. ”

OUR PREVIOUS FREE INFORMATION DAYS

July 2017
Liverpool

February 2018
London

September 2018
Newcastle

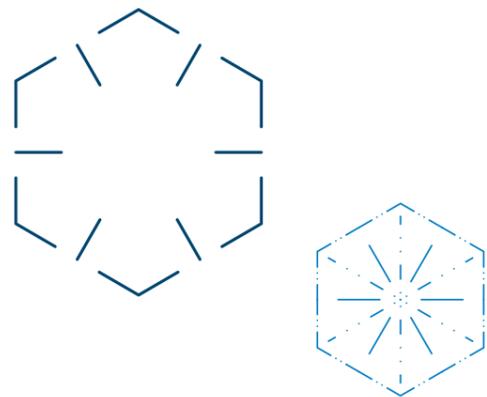
March 2019
London

September 2019
Manchester

UPCOMING

March 2020
London





DMD HUB WEBSITE

DMDHUB.org

Industry representatives and parents of patients have praised the DMD HUB Clinical Trial Finder, which Duchenne UK started last year. It is the first purpose built trial finder website for Duchenne Muscular Dystrophy anywhere in the world. (We believe it has global potential and are already talking to an international charity about the possibility of creating something similar in other countries.) More than 400 people are now signed up to receive our newsletter, alerting people to new trails for DMD as they come online. We know this is an invaluable resource. Feedback from

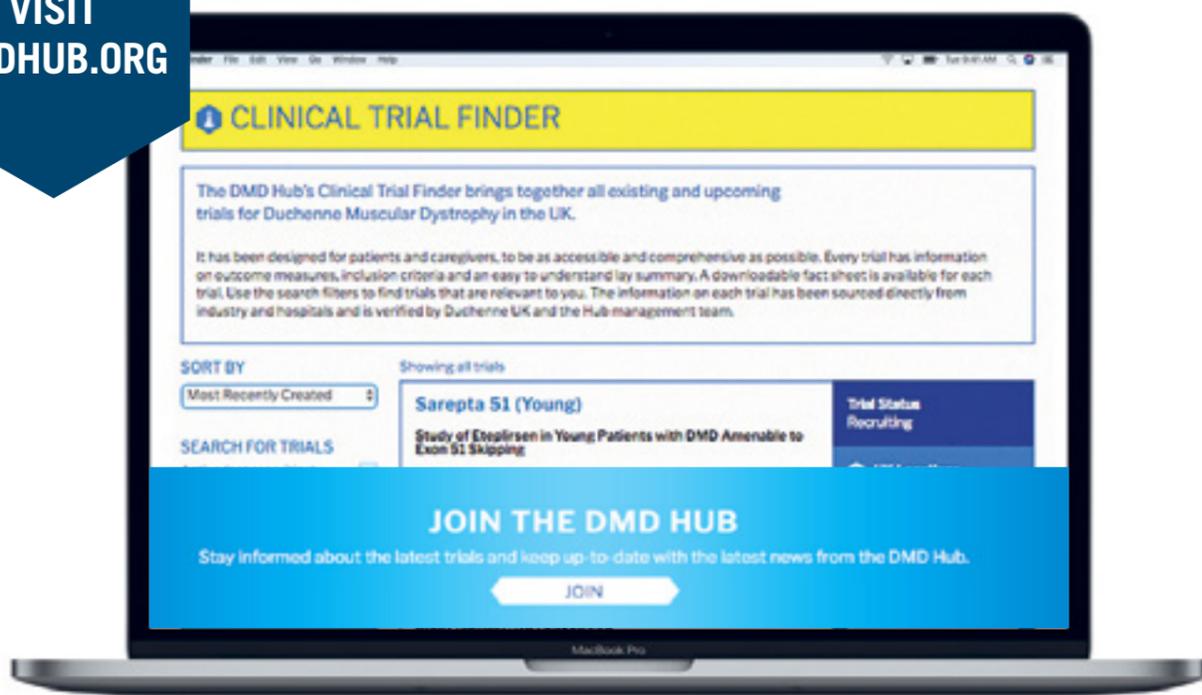
parents tells us that they are delighted to be able to easily access jargon free information about trials, for which can potentially benefit their children - where they are run, how to apply, and what criteria they need to fulfil to be considered.

This year, we have expanded the site to include a toolkit with resources for hospitals and drug companies wishing to launch and run a clinical trial. Families with Duchenne are in a race against time to save their children's lives. The DMD Hub clinical trial finder is vital tool helping to achieve that goal.

“ I think the most important development to increase trial capacity in the UK for patients with Duchenne muscular dystrophy (DMD) is the DMD Hub which is funded by Duchenne UK. The DMD Hub is a collaborative project between the experienced DMD clinical trial sites, the NIHR and Duchenne UK. ”

Professor Volker Straub, Harold Macmillan Professor of Medicine for the Institute of Genetic Medicine at Newcastle University

VISIT
DMDHUB.ORG



DMD FAMILY FOLDER

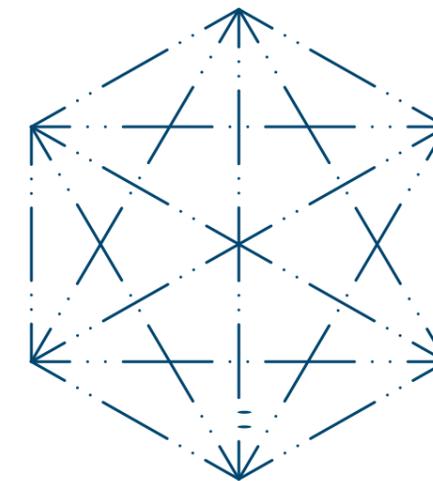
Supporting the newly diagnosed

Knowledge is power, so this year we have created a Family Folder.

The Family Folder brings together all the information a parent needs to know about the condition, how to look after their child and other family members. We share the knowledge we have acquired on everything from adapting the home, to how to get the best support at school, to accessing financial and emotional help.

This information pack is available in a paper version or online. We have placed them with neuromuscular consultants. Many North Star sites provide folders as part of their diagnosis meetings, but you can also apply for a folder to be sent to you on the Duchenne UK website, under Patient and Parent Resources.

We have sent out more than 500 copies.



“ Your folder has already given me so much valuable information which is helping me to understand and (slowly) come to terms with our situation. ”

“ What a brilliant resource, it literally covers everything that's important around and after the time of diagnosis. There is so little info and support given to parents at the time of diagnosis, the folder really addresses that. ”



DECIPHA

Giving DMD kids the support they need in school

We're here to save lives, but we're also here to help children live their best lives. School is a hugely important part of that. But kids with DMD have specific needs, and getting them the support they need can be an uphill struggle. That's why we gave the a not-for-profit community interest company DECIPHA £80,000.

The group has directly helped 117 families since we started our funding two years ago. It offers free educational support to children and young adults with DMD.



Charlotte Wakeling, mother of Felix, has received support from Decipha. She said:

“ My son is starting school in September and like most parents, I'm feeling apprehensive, but with Duchenne there are even more worries to consider. I was in touch with Duchenne UK's cofounder Alex about my concerns, and she immediately put me in touch with Nick Catlin at Decipha.

Contacting Nick was the best thing I could have done, what an inspirational man! Talking to him really alleviated my worries about Felix starting school and gave me practical advice about the EHC Plan process.

Nick was not only able to give advice from a professional point of view, but as a parent too, which I think is so very valuable.

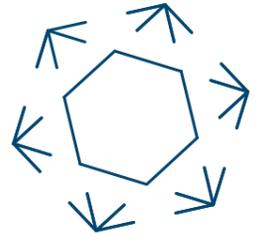


NEUROMUSCULAR COMPLEX CARE CENTRE

Forging a better future for adults with DMD

More people with DMD are living into adulthood. But they have complex needs with many different appointments with many different specialists - ranging from critical care consultants to dieticians. Duchenne UK is working hard to help them too. The National Hospital for Neurology and Neurosurgery in Queen Square in London has developed a new model to co-ordinate adult DMD patient

care. Patients are admitted for a short stay at a dedicated unit where they can see all their specialists in one go. This is hugely beneficial and we want to see this rolled out across the UK. This year Duchenne UK and Joining Jack have jointly committed £20,000 to help develop a Neuromuscular Complex Care Centre North East (NMCCC NE).



Benefits of joined up adult care:

- Reduce hospital appointments
- Reduce unplanned emergency admissions, especially intensive care admissions
- Facilitate transition from paediatric to adult services
- Provide access to new services for adult patients
- Deliver and advance clinical research

DMD PATHFINDERS

Working together to improve adult care

We are committed to working with adults who have DMD. DMD Pathfinders is the first user-led organisation run by and for adults with DMD and provides a unique perspective. We work closely with the organisation and want to thank them for their continuing input into our projects.



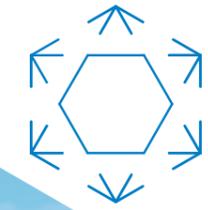
THE DUCHENNE DASH

The Duchenne Dash is a bike ride like no other. Participants ride 300km from London to Paris in 24 hours to raise money for Duchenne UK. It is exhilarating, it is exhausting, it is emotional - it has also raised **a million pounds** each year for the last three years. People come back time and time again because they love the challenge and recognise the tangible difference their hard work makes to the lives of people with Duchenne.

Get involved. Ride it. Become a corporate sponsor. Volunteer. Fundraise.

THE DASH HAS RAISED MORE THAN £4.5 MILLION SINCE 2013

“ For a relatively big bike ride it feels so intimate. ”



With huge thanks to Channel 4 anchorman Krishnan Guru-Murthy, the founder of the Dash and a patron of Duchenne UK. And with thanks to everyone from the first 30 cyclists in 2013 to the 160 who took part in 2019.

“ Cycling down the Champs Elysee flanked by motorcycle outriders after such a challenging ride was one of the most exciting and emotional moments of my life. ”

“ The rolls royce of bike rides. ”

“ I'm so proud of what I achieved personally on the ride, and I'm so proud to have been a part of what this amazing charity is achieving. ”

WATCH THE FILM



Check out the website dash.duchenneuk.org and scan here to watch the video of this year.

FAMILY AND FRIENDS FUNDS

Our most passionate fundraisers are those who live with Duchenne everyday - the families with a Duchenne child, their loved ones and friends. They understand how desperate the need is for treatments for this devastating disease. And how quickly they are needed. It is complicated and time-consuming to set up a charity, so we offer specially dedicated funds

within Duchenne UK. We support them, from creating a logo to helping them with fundraising. In addition, Family Funds can nominate the areas of research where they want their money to be spent, so their fundraising can be tailor-made to the aspects they feel are most important.

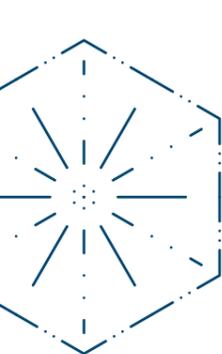


We'd like to welcome 6 new funds this year:

- Henry's Hurdles
- Moving Muscles for Marcus
- Joe's Journey to end Duchenne
- Action for Zach
- Cure4George
- Following Felix

And we'd like to thank all of our Family and Friends Funds for their continuing support. They are our front line troops in this battle to End Duchenne.

- Smile with Shiv
- Help Harry
- Chasing Connor's Cure
- Team Felix
- For Felix
- The Lygo Family Fund
- Team Dex
- Muscles for Mitchell
- William's Fund
- Jack's Aim
- Lifting Louis
- Jacobi's Wish
- Project Go
- Jack's Mission
- Ralphy's Fund
- Action for Arvin
- Archie's March



Lisa Kuhwald, Team Felix

“ I have a fund called Team Felix, named after my little boy Felix who was diagnosed with Duchenne back in 2013.

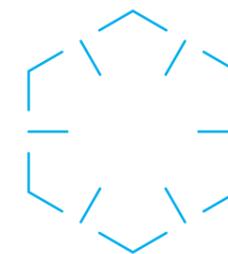
The reason we fundraise for Duchenne UK is because they ring fence 100% of the money that we raise and only spend it on research so we can really see exactly where our money is going.

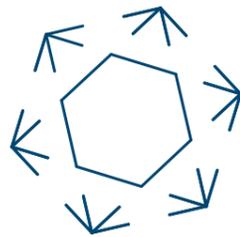
They also ask my opinion on potential projects and we are able to decide which of their many research projects to put our money towards.”



PARTNER CHARITIES

We can't do it alone, and we don't do it alone. We are so grateful for the support of our partner charities here and abroad, as they join us to force through change for this generation of boys:





CORPORATE SUPPORT

The support we receive from businesses is an invaluable part of our fundraising.

There are many ways we can work with firms, so get in touch and make us your Charity of the Year. Many companies return year after year to our charity, impressed by the wide-ranging impact of Duchenne UK, its cost effectiveness, and its positive pioneering attitude. Duchenne UK was set up by mothers

to save their sons, and is supported by parents across the UK. Its message is powerful, moving and impactful — engaging all workers from the shop floor to senior management. We can support companies that make us their Charity of the Year by offering literature and speakers, fundraising ideas and much more.

We are incredibly grateful to the support we receive from businesses which have backed Duchenne UK in 2019. We'd particularly like to thank:

- Foodbuy
- Clarke Willmot
- Marshall Wace
- CMS



Spotlight on FOODBUY

This year Foodbuy, a leading group procurement organisation, has extended its charity partnership with Duchenne UK for a further two years. In the three years they have been involved with us they have contributed £350,000. Staff have pulled together to raise this incredible sum by carrying out a number of challenging, fun and inspirational events. They've hosted a gala dinner which raised a phenomenal £125,000, completed the Three Peaks Challenge, run half marathons, held culinary masterclasses and have carried out bake sales. They also sent a team to take part in Duchenne UK's flagship event — the Duchenne Dash, cycling more than 300 kilometres in 24 hours.

We'd like to send our heartfelt thanks to each and every member of Foodbuy who has given up their time and energy to raise money for Duchenne UK. Their hard work is changing lives.

SARACENS

Without the support and the money you bring, we simply would not be where we are today.

Saracens, one of the best teams in English Rugby Union, is throwing its, not inconsiderable, muscle behind Duchenne UK to tackle DMD. The rugby club has announced a two year partnership with Duchenne UK to raise awareness and significant funds for pioneering research to find treatments of Duchenne Muscular Dystrophy.

It's the result of a long-standing relationship between the charity and the club thanks to the Farrell family. Owen and Andy Farrell have

campaigning for many years for the charity Joining Jack, a founding partner of Duchenne UK. Their close friends, Andy and Alex Johnson, set up Joining Jack for their son who has Duchenne Muscular Dystrophy.

England captain Owen Farrell's iconic conversion celebration sees him create the 'JJ' salute, hooking his forefingers to make the initials of Joining Jack, and highlight Duchenne Muscular Dystrophy to sports lovers around the world.

Owen Farrell, Saracens fly-half and England captain, said:

"I've been a proud supporter of Joining Jack for over five years now and it is a cause close to my heart. The courage of Jack, Eli and all of the boys with DMD is very inspiring and I'm really happy to see that Saracens are joining forces with Duchenne UK to help tackle this devastating disease."

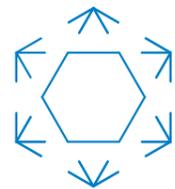


Among the many exciting partnership opportunities with Saracens, Duchenne UK is delighted to be showcased at the much anticipated Gallagher Premiership fixture against Harlequins at Tottenham Hotspur Stadium on Saturday 28 March 2020.

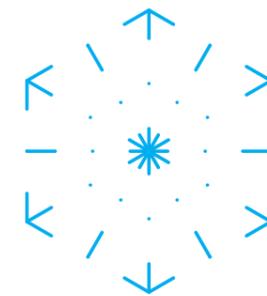
Lucy Wray, Saracens board member, said:

"I'm really excited about our partnership with Duchenne UK. At Saracens, family is at the heart of everything we do. We want everyone that comes into contact with Saracens to feel like they are part of this big family and we extend a very warm welcome to Duchenne and all the families affected by Duchenne Muscular Dystrophy."

THANK YOU FOR YOUR SUPPORT

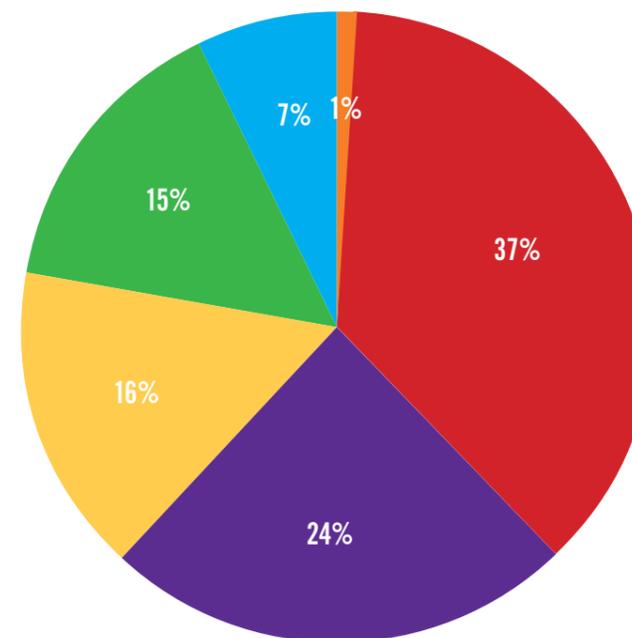


ACCOUNTS



PROJECT EXPENDITURE

Since 2013 Duchenne UK has committed to £14m of direct grants to 86 projects.

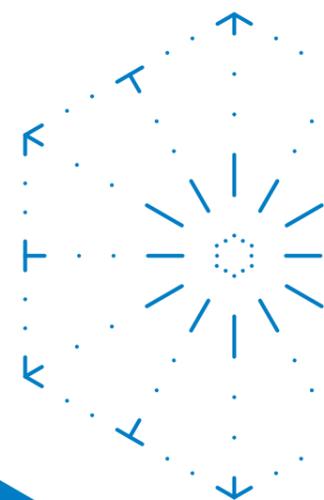
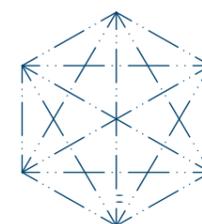


PROJECT EXPENDITURE

- 37% Research Into New Drugs
- 24% Repurposing Drugs
- 16% Expanding Trial Capacity
- 15% Gene Therapy
- 7% Approval & Reimbursement
- 1% Other

90P
IN EVERY £1 RAISED
IS ALLOCATED
TO RESEARCH

86
PROJECTS
FUNDED



Duchenne UK is proud to be a member of the Association of Medical Research Charities (AMRC). Our grant giving policy conforms to their high standards. All grants go through a meticulous peer review by our Scientific Advisory Board and Patient Advisory Board before seeking final approval from the Board of Trustees.





WWW.DUCHENNEUK.ORG

Join us to end Duchenne

INFO@DUCHENNEUK.ORG

CHARITY NUMBER 1147094