Duchenne UK

Impact Report

2024: The Breakthrough Year

Contents

Cover image: Emily Reuben OBE, Co-founder and Chief Executive of Duchenne UK and Sarah Smedley, whose son Oscar has DMD, before they set off on the Duchenne Dash 2024

Message from our Founders

It's not an understatement to say that 2024 was a BREAKTHROUGH YEAR for Duchenne muscular dystrophy (DMD) families in the UK. It was bookended by not ONE but TWO new treatments being approved. And this impact report is all about the POWER of patient advocacy and of patient funded research: because Duchenne UK played a pivotal role in making both of those happen and it's something we as a community need to be proud of!

The year began with the approval of vamorolone, a drug that we first funded ten years ago. In January, the National Institute for Health and Care Excellence (NICE) gave it a positive opinion, which means it will now be available on the NHS for all patients, aged four and above.

And just before Christmas, a second drug, givinostat, was approved by the Medicines and Healthcare products Regulatory Agency (MHRA) for all patients above the age of six. It was given conditional approval for the non-ambulant. NICE will make a decision on whether to fund this in 2025. The Duchenne community responded to our call for action to get givinostat approved with passion and energy. More than 200 families wrote to the MHRA to plead the case for a broad approval. And our voices were heard.

More needs to be done to help the NHS deliver these treatments. Our fight continues into 2025.

It was also a landmark year in other ways: we held our first ever conference, New Horizons. We developed the first alpha prototype of our upper body mobility device, called Elevex.

In spring we received our OBEs. And in 2024 Her Majesty The Queen renewed her patronage of Duchenne UK.

The theme of this year's report is power – the power of patients to make change.

Change is what Duchenne UK is all about – identifying challenges and coming up with practical, powerful and strategic solutions.

Thank you for your support.

With love and thanks,
Emily Reuben OBE, Chief Executive of Duchenne UK
Alex Johnson OBE, Chief Executive of Joining Jack Duchenne UK Founders

Our Impact - the headlines

2024 – Breakthrough year

Real changed happened in 2024, as we helped push through TWO new treatments. Here are some of our major achievements this year:

OUR IMPACT IN 2024 – FUNDING RESEARCH AND IMPROVING LIVES

£270,000 for new heart research

New emergency APP goes live

Givinostat: second new drug approval

Respiratory guidelines published by DMD Care

DMD CARE UK best care for all

In Case of Emergency

ELEVEX

DMD HUB Covering the nations

Duchenne UK Conference 2024 NewHorizons

Vamorolone: first new drug for DMD approved

Elevex arm-assist prototype showcased

Our first New Horizons conference

Data Collection platform goes live

Project HERCULES pushes for new treatments

Our rare reality report fights for change

Her Majesty The Queen renewed her patronage of Duchenne UK

HERCULES.
DMD: HEALTH RESEARCH COLLABORATION UNITED IN LEADING EVIDENCE SYNTHESIS

Developing vamorolone - a Venture Philanthropy approach

2015 We funded Phase I.

After a nearly decade of hard work we are delighted to announce that vamorolone received approval for use on the NHS this year. Current corticosteroids can be badly tolerated and have significant side effects - vamorolone is the first real alternative for patients and doctors.

Our role

We invested in and supported this drug from start to finish - from the original research in the laboratory to presenting evidence to win approval through health technology assessments. The journey began in 2015:

- **Raising** £750,000 for the initial funding for Phase 1 clinical trial with our partners charities Joining Jack and the Duchenne Research Fund.
- **Helping** win €6 million investment from the European Union for Newcastle University and the drug company ReveraGen for the Phase 2 clinical trial.
- **Funding** the person who ran the Phase 2b trial, Professor Michela Guglieri from the John Walton Muscular Dystrophy Research Centre at Newcastle University, and the hospital sites which delivered it.
- **Collaborating** with ReveraGen to select the outcome measures for Phase 2 and 3 trials, providing clinical meaningfulness to the data collected.
- **Creating** the award-winning Project HERCULES. This groundbreaking initiative brings together rival drug companies to develop tools to speed up approval of drugs by agreeing on and providing evidence for health technology assessments used by NICE.

"The approval of vamorolone is the result of years of hard work and collaboration by scientists, clinicians and patient advocacy groups spearheaded by Duchenne UK. The venture philanthropy model we use means any money returned to us is reinvested in research for new DMD treatments. We offered targeted and sophisticated support through every stage of the journey. To finally see this new drug being given to patients is a huge success story and testament to our drive and determination to improve outcomes for DMD families."

Emily Reuben OBE, Chief Executive of Duchenne UK
Alex Johnson OBE, Chief Executive of Joining Jack
Duchenne UK Founders

Some of the key people behind the development of vamorolone - Sheli Rodney (Duchenne Research Fund), Emily Reuben OBE (Co-founder and Chief Executive of Duchenne UK), Professor Katie Bushby (Newcastle University), Professor Michela Guglieri (Newcastle University), Alex Johnson OBE (Co-founder of Duchenne UK and Chief Executive of Joining Jack), Professor Eric Hoffman (Binghamton University)

2024

In January vamorolone was approved by the MHRA as an alternative to existing corticosteroids

Approved by NICE to treat patients aged 4 and over

How we made vamorolone a reality

Duchenne UK

Phase 1 Funding

£750,000

Duchenne UK, Joining Jack and the Duchenne Research Fund fundraising for Phase 1 trial.

Phase 2 Clinical Development

We worked with the company to select the outcome measures for the Phase 2 and Phase 3 trials, which gave clinical meaningfulness to the data.

Phase 3 Clinical Development

Funding the study chair of Phase 2b trials, Professor Michela Guglieri, and UK hospital sites.

Phase 4 Collaboration

Helping win €6 million in EU funding for Phase 2 research supporting Newcastle University and ReveraGen.

Phase 5 Value Assessment and Access

HERCULES

Instigating Project HERCULES to speed up drug approval processes.

Phase 6 NHS Adoption

NHS

DMD Care UK educating families and NHS staff to ensures patients receive it quickly and safely.

VENTURE PHILANTHROPY making money from our investments and reinvesting it in new research for treatments

We have supported DMD treatment vamorolone at every stage of its development

Givinostat approval - the power of advocacy

In 2024 Duchenne UK led a hugely successful campaign for the approval of a new drug for DMD, givinostat, for people who are ambulatory (able to walk) and non-ambulatory (who cannot walk). Then we discovered that although approval had been granted, nobody was actually being dosed with the drug, despite the company giving it free-of-charge to the NHS. So we launched our #TimeisMuscle campaign to galvanise our committed parent community to lobby MPs and health authorities to right this wrong.

Our fight for approval:

The givinostat trial was run at first on ambulatory boys, showing evidence that the drug reduced inflammation and muscle loss.

This wasn't enough for us. We want ALL people with DMD to have the same access to givinostat. We called on the Medical and Healthcare products Regulatory Agency (MHRC) to give the drug what's called a broad label - so anyone with DMD could have it, including those who are non-ambulatory.

More than 200 families joined our campaign, writing to the MHRA. And through the power of our advocacy our voices were heard.

On 20 December the MRHC agreed, and allowed all patients aged six and over to start treatment when ambulatory, and issued a conditional approval for non-ambulatory patients.

Our fight for access:

The drug became available through the Early Access Programme, but by November we discovered that no one had been dosed with it. Again we turned to our patient community for help, launching our #TimeisMuscle campaign.

Hundreds of families wrote to their MPs, GPs, Health Trusts and to the MRHA. Thanks to them, questions were raised in the House of Commons. Our co-founder Alex Johnson met the Secretary of State for Media, Culture and Sport, the Rt Hon Lisa Nandy MP.

By the end of 2024 no one had actually been dosed with givinostat - but we will not give up on our fight for it and will keep campaigning until it happens.

Mail Online

Jack was given a pioneering drug to beat muscle wasting disease and can still stand. His best friend Eli didn't get the drug and now he is permanently in a wheelchair. Their contrasting stories prove new treatment works, so why is the NHS rollout at risk?

Joey Levene, who has DMD, meeting his MP Christian Wakeford, to discuss access to givinostat

Alex Johnson OBE, Co-founder of Duchenne UK and Chief Executive of Joining Jack, and her son Jack who has DMD, meeting Rt Hon Lisa Nandy MP, Secretary of State for Media, Culture and Sport, to discuss our #TimeisMuscle campaign

Autumn 2024
Givinostat is made available for free to the NHS through an Early Access Programme (EAP).

Time is muscle

Mid-November
No one has received Givinostat - #TimeisMuscle campaign launched.

November 2024
Duchenne UK writes to all 24 NHS trusts in the NorthStar clinical network, with MDUK, calling for clinics to get the funding they need to take part in the EAP.

November 2024
We encourage families to write to MPs and the MHRA, an incredible 200 families respond.

December 2024
MPs start to take action, one sends a question sent to the Department of Health and Social Care and another sends a question to the Secretary of State.

December 2024
Politicians begin meeting DMD families.

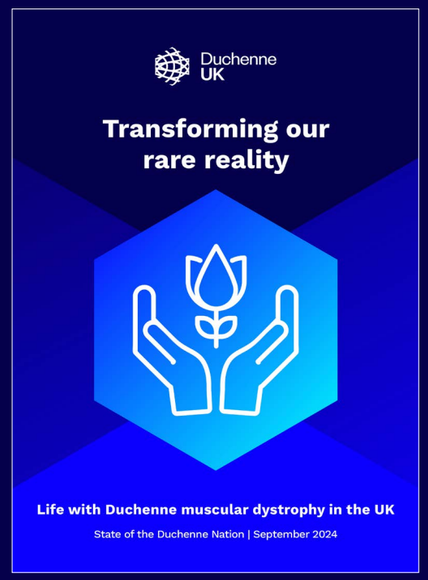
End of December
The MHRA approves givinostat for ALL people with DMD.

Campaigning for change

DMD is a complex condition and changes over time. The needs of a six-year-old with DMD are very different to those of a sixteen-year-old, both physically and emotionally. The goalposts are constantly changing. We work hard to raise awareness and increase understanding of DMD.

This year, on World Duchenne Awareness Day, we launched our first ever policy report *Transforming our rare reality.* The paper sets out how people with DMD are not getting the care, treatment or assistive technology they need to manage their condition. It offers practical and productive solutions. Recommendations include the amalgamation into NICE's care guidelines of the DMD Care UK guidelines, and urging the UK government to increase trial capacity at existing Centres of Excellence.

In November one of our founders, Emily Reuben, was elected onto the Board of the Association of Medical Research Charities (AMRC). In this role, she will make sure the voice of the DMD community is heard right at the centre of a key organisation fighting to improve and influence medical research in this country.



Helping the DMD Heart - the power of research

There have been huge strides in DMD research in the last decade, but research into the heart has lagged behind. People can now live longer with DMD because of improved multidisciplinary care - but only if their hearts are strong enough. In February we launched a grant call of £500,000 for research specifically into the DMD heart.

By the end of the year we had funded two projects - including one for the repurposing of a drug approved for heart failure, empaglifolozin, which is used to treat DMD cardiomyopathy. We have identified three more research areas which we are assessing for funding.

We'd like to thank The Patrick Trust - who committed £200,000 for cardiac research into DMD heart conditions - as well as Joining Jack and Alex's Wish for their financial support for our 'Help the Heart Call'.

"The Patrick Trust is very happy to be joining forces with Duchenne UK, Joining Jack and Alex's Wish on this crucial area of research. Timely access to the right cardiac treatment can be game-changing in the overall care of people with Duchenne muscular dystrophy, and we hope to fund research that makes a significant difference to it."

Julian Pritchard, trustee of The Patrick Trust

Help the Heart

Our trial site network

Established in 2016 in partnership between Duchenne UK and the John Walton Muscular Dystrophy Research Centre at Newcastle University, the DMD Hub is the UK clinical research network for Duchenne muscular dystrophy. The DMD Hub exists to enable and accelerate delivery of clinical trials in the UK for the benefit of patients, clinical sites and industry. It now operates in 11 locations: Alder Hey, Birmingham, Bristol, Glasgow, Leeds, London (Great Ormond Street Hospital and Evelina), Manchester, Newcastle, Oswestry and Oxford. At the end of 2024 the Hub had run 57 trials with a total of 574 participants since it launched.

Our Research Portfolio

We never stop looking for new transformative treatments - offering regular research calls. This year we launched a £1-million pound Therapeutic Grant Call. This helped us identify two exciting projects focusing on getting new gene replacement therapies into the clinic. The £500,000 Help the Heart Call has funded two projects. With other charities, we supported research into how DMD effects the brain. We also funded a study to improve clinical care, looking at saline solutions which help restricted breathing.

Our partners - the power of collaboration

There is strength and power in collaboration.

We are nothing without our trusted partners, our dedicated DMD families, their friends and supporters. Duchenne UK goes from strength to strength thanks to our belief in and commitment to collaboration.

For ten years we have partnered with the incredible team at the John Walton Muscular Research Centre in Newcastle. We were honoured to attend and speak at their anniversary event.

THE John Walton MUSCULAR DYSTROPHY RESEARCH CENTRE

DMD HUB

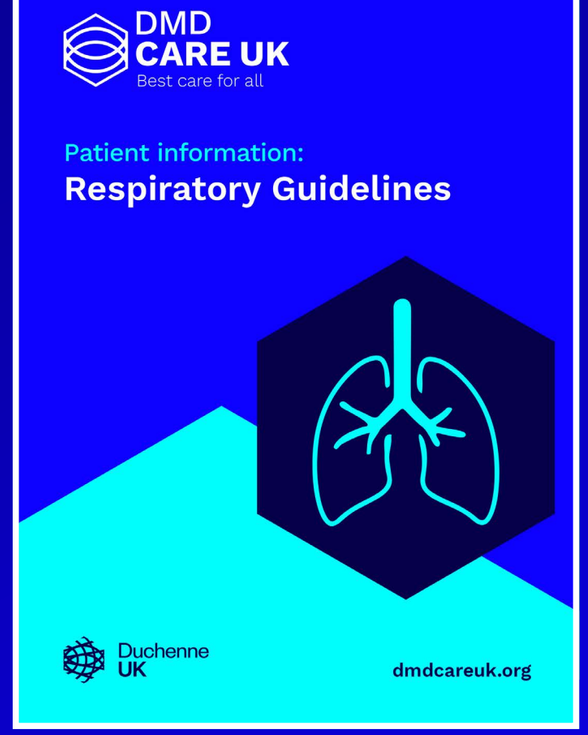
Duchenne UK

DMD CARE UK Best care for all

Our mission to improve care through the DMD Care UK programme is brought about by the support of our amazing partner charities: Alex's Wish, the Duchenne Research Fund and Joining Jack. A huge thank you to them.

In Case of Emergency

Emily Reuben OBE, Co-founder and Chief Executive of Duchenne UK, and Alessandra Gaeta, Director of Research and Development at Duchenne UK, with the DMD Hub team



DMD Care UK update

DMD Care UK is a nationwide initiative to ensure every person living with DMD in the UK has access to the best care, no matter where they live. To that end we are producing best practice care guidelines on every aspect of the care needed for a person with DMD. This year we have published our respiratory care guidance, and have set up a working group for our next guide which will be on supporting the transition to adult care. And we are beginning work on our guide for the drug vamorolone. This year our new In Case of Emergency APP has also gone live.

DMD Care UK is a collaborative initiative between the John Walton Muscular Dystrophy Research Centre at Newcastle University and Duchenne UK, embedded in the UK North Star Network. It is funded by Duchenne UK, Duchenne Research Fund and Joining Jack.

In Case of Emergency APP
A legacy of love

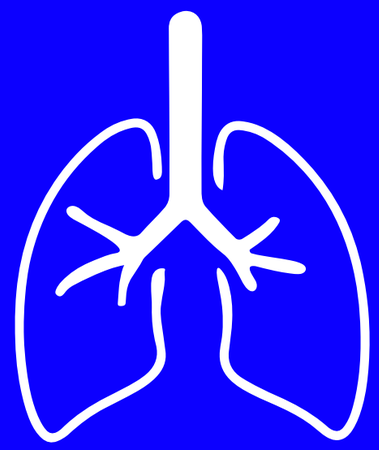
Our new APP supports people who find themselves in a medical emergency. The downloadable APP allows you to keep track of the medical needs of someone with DMD, holds emergency contacts, and shares guidance for medical professionals on treatment in emergencies.

It includes ‘Shiv’s recommendations’ in memory of a 12-year-old boy with DMD who died. It’s a four-point checklist designed to empower and support DMD families who may find themselves in a medical emergency at A&E. It was created by his parents as a lasting legacy of their love for their son.

Supporting transition to adult care
We have launched a new working group on the transition from paediatric to adult DMD care. We are also funding a project led by Dr Anne-Marie Childs in Leeds to gather evidence to support the group.

Guidance on vamorolone
We established a working group to produce guidance on the use of vamorolone following its approval for use in NHS England.

Respiratory care guidance
We have published our guide on respiratory care which looks at how to maintain health, offers guidance for clinicians and details how to deal with emergencies. It’s endorsed and supported by the British Thoracic Society and was published in Thorax, an international respiratory and clinical care journal.



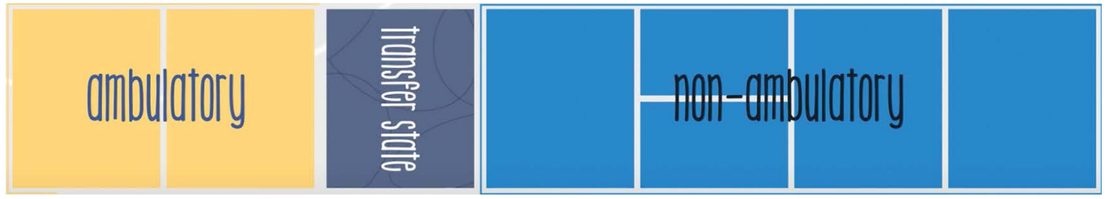
Project HERCULES - plotting the course of Duchenne to help target treatments

Our award-winning Project HERCULES, which was set up to speed up the approval and payment process for new drugs for DMD, published a key piece of work this year. The Natural History Model Project is the result of the collaboration of patient organisations, clinicians, academics and leading international pharmaceutical companies. It documents in detail how the disease progresses. Better understanding of this will allow more targeted approaches to treatments.

The model identified a new stage in the progression of DMD called the Transfer State. This is when people can no longer walk/run 10 metres but can still stand and can support transfers to a bed, sofa or toilet. Up until now assumptions about length of life did not take into account this clinically important stage.

HERCULES

The Natural History Model will be a powerful tool in understanding and treating DMD. To help explain how it works and what it means, and to give details about the newly identified Transition stage, we have created a piece of animation. This is being translated into numerous languages and we hope it will become an important tool in increasing understanding of the disease.



The different stages of the Natural History Model

Duchenne UK - a global leader

Duchenne UK's groundbreaking work is being replicated around the world, showing that our far reaching and innovative approach to a rare disease is changing the sector for the better. This year the models for Project HERCULES and the DMD Hub have been implemented in other disease areas.

BMD Hub

This mimics our own DMD Hub. It was set up this year to support clinical trials and participation in clinical research for people with Becker muscular dystrophy. It's run in collaboration with UK patient organisations with an interest in dystrophopathies - conditions caused by certain mutations in the DMD gene. It's funded by Edgewise Therapeutics and is coordinated by the John Walton Muscular Dystrophy Research Centre at Newcastle University.

SMA Care UK

Also set up this year, and using our DMD Care UK programme as a blueprint, this was established by clinicians and patient groups to update and implement UK Standards of Care for people of all ages living with Spinal muscular atrophy (SMA).

Project Mercury

Set up last year and modelled on our own Project HERCULES, this is led by Facioscapulohumeral muscular dystrophy (FSHD) patient advocacy organisations in partnership with biopharma companies, researchers and experts in the field. They work together to overcome specific challenges which slow or stop the development and delivery of therapies for people with FSHD around the world.

Global impact

We are very proud to see our creative and collaborative approach to making change in DMD making a real difference in other rare diseases. We look forward to developing further programmes that can lead change and help the people who need it most.

Her Majesty The Queen renews patronage of Duchenne UK

After a review of Patronages by the Royal Household, we were delighted that Her Majesty the Queen, formerly Her Royal Highness The Duchess of Cornwall, chose to continue her role as President of our charity. This year marks a decade of support of Duchenne UK by Her Majesty the Queen. Her patronage has played a vital role in the growth, development and impact of the charity.

"We are so grateful to Her Majesty The Queen for choosing to continue her patronage of Duchenne UK. She has been incredibly supportive of the charity and our community, which has meant so much to us. Her patronage helps raise the profile of a rare disease and shine a light on our work. Her support is an important source of strength for the charity."

Emily Reuben OBE, co-founder and Chief Executive of Duchenne UK

New Horizons conference - the power of community

In March we held our first ever conference - New Horizons. Dozens of researchers, clinicians, members of the Duchenne UK community and representatives of drug companies spoke at the packed event in central London. We were delighted to welcome 240 delegates, and were particularly pleased to see dozens of families of people with DMD.

Living with a rare disease can be an isolating experience, and our conference provides an opportunity to meet other people living with and supporting people with the condition. New Horizons is an example of how Duchenne UK constantly strives to find the new ways to allow parents to inform themselves and fight for the best care for their children.

We covered a wide variety of topics, such as the latest research into treatments, how to manage the physical, mental and educational support for people with DMD, and the latest developments in assistive technology. There was even an opportunity to ask questions to the drugs companies leading research into this area.

It was an inspirational, information packed and motivational event and we look forward to our next one. Thank you to everyone who attended.

Duchenne UK Conference NewHorizons

"There was so much amazing information. I understand far more now about how the condition changes the muscles. How the trials work, how the drugs work, the different types of trials."

"Thank you for giving us the opportunity to experience something special."

"I feel that I have learnt so much more in two days at New Horizons than I have in the last six months since diagnosis."

"New Horizons is setting a very high standard – the optimal balance between science and care, emotions and fact."

Elevex - Innovative technology to support upper body mobility

We are delighted to announce that our Elevex project - which uses innovative technology to assist people who are losing upper body movement - is now award winning! This year it won two prizes at The Engineer awards, in the Healthcare and Medical category and the overall Grand Prix award. This is testament to the hard work of our amazing team.

Elevex is a first-of-its-kind soft exoskeleton designed to help people with progressive neuromuscular diseases like DMD and SMA continue to use their upper limbs. The loss of upper body mobility has been described by many in the DMD community as more devastating than stopping walking. It takes away their independence and ability to do many things they love such as playing instruments, gaming or taking part in sport. We at Duchenne UK have made it a priority to do something about this.

Since taking on the project in 2022 we have raised more than £2 million - thanks to a £1.25 million award from People's Postcode Lottery's Dream Fund and £800,000 raised through our partner charities, major donors and Friends and Family Funds. We've done in-depth research and built and tested four working prototypes with our partners the Spinal Muscular Atrophy UK charity and the University of Liverpool's Inclusionaries Lab.

As a charity we look to collaborate with and support innovators in the field to fulfil our big ambitions. We've worked with experts in exoskeleton biomechanics at the University of Central Lancashire and design engineering experts at Frazer Nash Consultancy. We are continuing to refine and test our technology and are now well on our way to Elevex becoming a reality.

ELEVEX

Showcasing our technology on a global stage

This year we were invited to speak at the South by Southwest (SXSW) technology conference in Austin in Texas, and were delighted that a BBC team came along to make a documentary about it. We were selected as part of the Future Art and Culture programme produced by British Underground and Arts Council England with parternship support from the British Council.

One of our founders Emily Reuben OBE addressed the conference. She spoke movingly about the vacuum of technological support for people with advancing neuromuscular conditions like DMD. She told delegates that her frustration with the status quo had led to Duchenne UK taking the driving seat in filling the gap by advancing assistive technology and creating Elevex. Eli Crossley, Emily's 17-year-old son who is a musician with DMD, wowed the audience with a performance. He demonstrated the Elevex prototype and how it would allow him to continue to make music. He also spoke about how life changing it would be if the technology sector directed its skills towards supporting disabled people.

The technology reporter Nick Kwek made a documentary about it called Music Man. It followed Eli's story and showed how Elevex has the potential to support his music career. It was broadcast on BBC TV.

Also this year, we have continued to develop our new state-of-the-art wheelchair, which will greatly improve modern living for disabled people.

Emily Reuben OBE, Co-founder and Chief Executive of Duchenne UK, her son Eli who is a musician and has DMD, and BBC Producer Nick Kwek, speaking at the SXSW panel discussion

Inclusive technology takes to the stage at SXSW
We presented Elevex at this influential conference and discussed the power of inclusive technology.

Building a game changing data platform
We are developing a new data platform to improve care, allow access to trials, and better focus research into treatments.

Arm assist prototype Elevex unveiled
We delivered an alpha prototype of our arm-assist device ELEVEX. We will be testing it with users throughout 2025.

The wheelchair of the future
We are exploring concepts and designs for our new wheelchair.

Transforming lives through data - our new data platform

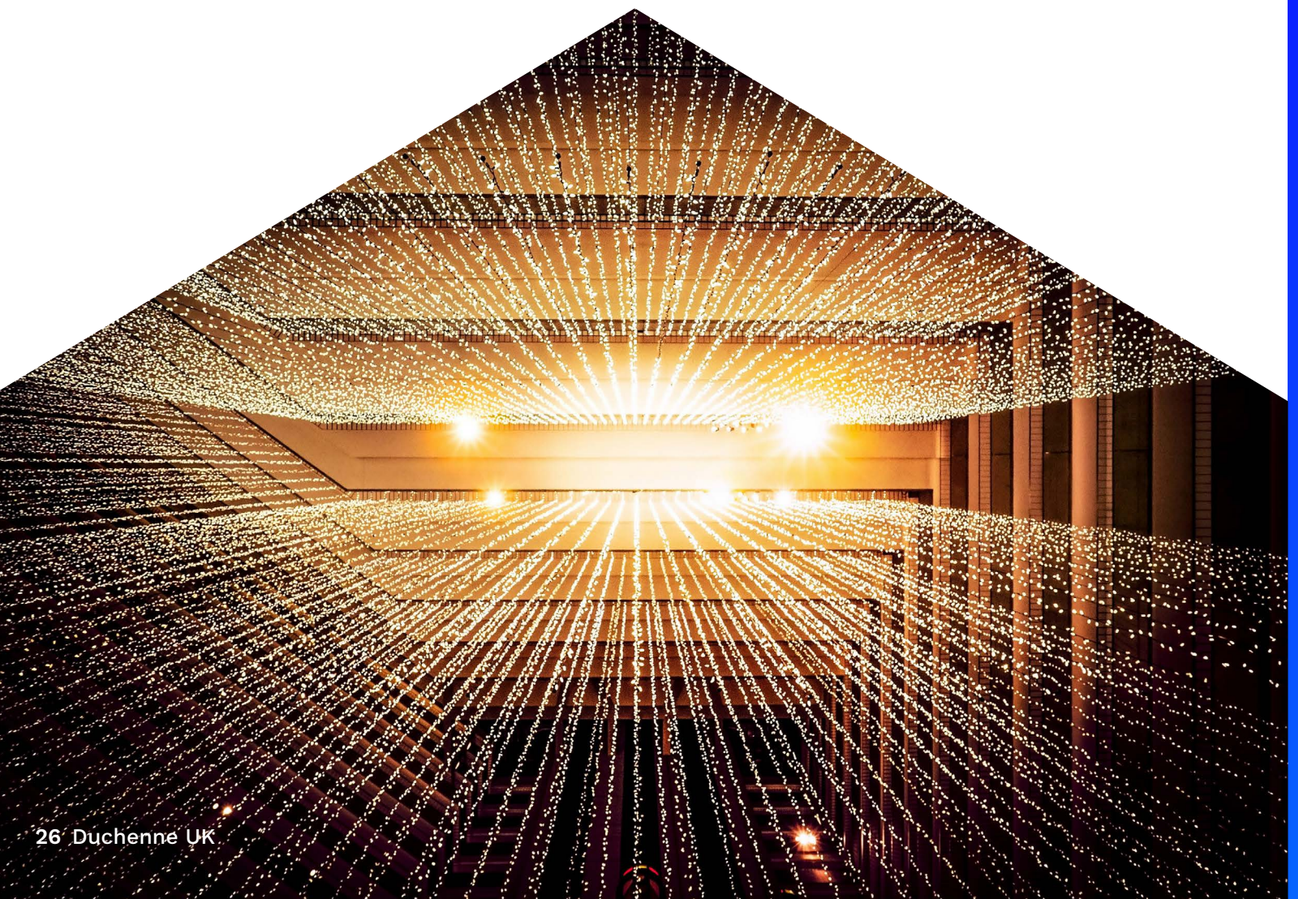
We believe patient data holds the power to drive meaningful change for people with DMD, so we have begun work on a new data collection platform. This will help clinicians improve care, and researchers develop better and more effective treatments.

This year we were awarded £500,000 from the Government's UK Research and Innovation fund to take part in an international project known as the Patient Lifestyle and Disease Data Interactium.

The idea is to empower patients and their families, researchers and clinicians by pooling information on a central database. It will build on our Central Recruitment Database, which matches people with trials, and other valuable resources we have developed.

Patients and families should be able to track disease progression allowing them to make informed decisions about their health and care. It will continue to offer excellent access to the most appropriate trials available. Clinicians will be able to use the demographics to better target treatments, support their delivery or focus on new areas.

This is another example of Duchenne UK's successful strategy of maximising the potential of our most valuable asset - informed, engaged and passionate parents who want the best for their children.



Emily and Alex receive their OBEs

Our Founders, Emily Reuben and Alex Johnson both received OBEs in the King's Birthday Honours list

Some of the cyclists taking part in the 2024 Duchenne Dash

Duchenne UK's fundraising community

Behind every ground-breaking Duchenne UK programme is an army of funders. They are what is driving us forward.

We are in awe of the energy of everyone who takes on a challenge to support our work, from the Duchenne Dashers to our mighty marathon runners. We so value our partnerships with the amazing and dedicated Family and Friends Funds and our charity partners Joining Jack, Alex's Wish, the Duchenne Research Fund, The Patrick Trust and Chasing Connor's Cure.

We really appreciate the support of People's Postcode Lottery and what it allowed us to do, and the teams at Foodbuy, Rabobank and Reynolds, who have been incredible.

Those who donate directly to us, giving large and small amounts, and those who leave money in legacies and in memory of someone, are so important to us.

Whichever way you've supported us, you make everything you have just read about possible. Your commitment today brings us closer to ending Duchenne tomorrow.

To everyone who has helped us this year, a huge THANK YOU!

Some of the TRAD UK team who held a golf day to raise money for Team Thomas, the Family and Friends Fund of their colleagues Danielle and Liam Ackers whose son Thomas has DMD

£29.2 million

raised since we set up Duchenne UK

Nathan Rudge skydiving to raise money for Duchenne UK

One of the Rabobank team who ran the Royal Parks Half Marathon to raise funds for Duchenne UK

In 12 years our amazing Duchenne Dashers have raised

£8 million

cycling from London to Paris

Rabobank's amazing support

We gained a wonderful new partner in 2024, Rabobank.

Its indefatigable team began supporting us after Luca, the son of David Mulroy who works at Rabobank, was diagnosed with DMD.

They have been so inventive at finding ways to support us, from donating the proceeds of the sale of furniture to the charity, to 26 members of the team taking part in the Royal Parks Half Marathon in October.

David and his wife Lindsey also cycled the Duchenne Dash in May, and were joined by a team from Rabobank!

Together, they raised **£164,618** by the end of 2024.

David and Lindsey Mulroy

Attendees at the Henry's Hills Family and Friends Fund gala dinner

Family and Friends Funds

We started with one in 2016. We now have over 50 Family and Friends Funds. They tap into and harness the power of those around them and make our whole community bigger and stronger. Together they raised approximately £368,000 in 2024, and funded a wide range of projects including the Therapeutic Grant Call, DMD Care UK Transition Project and Data Platform.

They did this by organizing a wide array of activities from taking part in sports challenges to holding galas.

Not only are they raising valuable funds, they are raising crucial awareness of DMD too, key for a rare disease.

Our Family and Friends Funds really are the heart of our community. Are you interested in finding out more about Family and Friends Funds, where you raise money under your own fund's name with our support, and proceeds go to projects run by Duchenne UK?

Do get in touch with **familyfunds@duchenneuk.org**

Some of the cyclists taking part in the 2024 Duchenne Dash

Askew, the band that Eli Crossley fronts, playing at the Duchenne Dash gala dinner in Paris

Our Dashers saddle-up for another epic cycle

Our Dashers got on their bikes for the 12th time in 2024 and cycled from London to Paris in 24 hours, raising £821,000. It was a special experience with veteran Dashers joined by first-timers, but all riding together and supporting each other.

Our co-founder and Chief Executive, Emily Reuben OBE took part, as did her husband Nick, and our Chair, the Channel Four TV news anchor Krishnan Guru-Murthy.

We then celebrated another successful ride with a gala dinner in Paris with live music from the band Askew, fronted by Emily and Nick's son Eli.

Keen supporters who couldn't join the ride to Paris contributed via the Duchenne Dash AT HOME, cycling locally to contribute almost £14,000 to the total.

If you would like to joins us for the next Duchenne Dash you can find out more and sign up for a place at **duchenneuk.org/dash/**

Taking on a challenge for Duchenne UK

We are so thankful to our incredible community of fundraisers who always amaze us with their creativity and commitment to Duchenne UK.

They have taken part in so many adventurous challenges. We are in awe of them!

Congratulations and well done to our team of dedicated runners who have taken on challenges for Duchenne UK this year, including raising £20,000 on the Royal Parks Half Marathon, £20,000 on the London Marathon and £2,700 on the Great North Run.

Danielle Ackers, whose son Thomas has DMD, and her friends climbed Mount Snowdon to raise money for her Family and Friends Fund Team Thomas

Emma Cutler, who ran four half marathons in October for Family and Friends Fund Ben vs Duchenne

Our charity partners

"Emily picked us up and gave us hope when Connor was diagnosed.

Not just pointing us in the right direction but injecting us with her passion and desire to change the course of DMD boys' lives.

"We are proud to continue to support Duchenne UK, with the annual Dash becoming a huge milestone for Chasing Connor's Cure, bringing our local community together to focus on smashing the fundraising target, year on year.

"We don't know where we would be without Duchenne UK and cannot thank them enough for their passion, determination and guidance."

Matt and Emma Crawford,
Chasing Connor's Cure

"It's wonderful to come to the end of another year of partnering with Duchenne UK and seeing how much we have achieved together and knowing that it will help people with DMD.

"I personally know the need for and value of our achievements, having a son who is 19-years-old and living with Duchenne."

Emma Hallam, Founder of Alex's Wish

Emma Hallam, Founder of Alex's Wish

"The Patrick Trust continues to support Duchenne UK, a cause very close to the family's heart.

"We always remain staggered at the drive and determination the team use to take the charity forward and to support everyone touched and dealing with Duchenne."

Julian Pritchard, The Patrick Trust

"Our partnership is so special to me. The approval of vamorolone for use on the NHS in England at the end of 2024 was a real testament to our partnership. We worked together and nurtured it from the beginning, so it was a real vindication of our commitment and determination."

Alex Johnson OBE, Chief Executive of Joining Jack and co-founder of Duchenne UK

"Our team at the Duchenne Research Fund has worked closely with Duchenne UK for over a decade. We really value collaborating and seeing the results of the vital research programmes we have funded together. It's a small community due to the rareness of Duchenne, but having partners like this is so valuable and really amplifies our effectiveness."

Sheli Rodney, Director of Operations, Duchenne Research Fund

Thank you to everyone who has supported us this year!

Thank you to our Family and Friends Funds and partner charities:

Access to Life
Action 4 Arvin
Action for Zach
Aidan's World
Archie's Army
Archie's March
Backing Jack
Ben vs Duchenne
Bruce's Battle Squad
Changing Charlie's Future
Chasing Connor's Cure
Cure4George
Defending William Against DMD
Doing it for Dexter
Edward Steam Team
Elliot's Endeavours
Fight for Finn
Following Felix
For Felix
Help Harry
Helping Hayden
Henry's Hills
Henry's Hurdles
Hope for Harry
Jack's Aim
Jack's Mission
Jacobi's Wish
Jayden's Army
Joe's Journey to end Duchenne
Kairo's Krew
Life & Hope for Lenny
Lifting Louis
Love for Leon
LucasFightingDuchenne
Lygo Family Fund
Mac My Day
Matthew's Mighty Mission
Mission Jensen
Moving Muscles for Marcus
Muscles for Mitchell
Oscar's Duchenne Challengers
Project GO
Ralphy's Fund
Smile with Shiv
Standing with Jack
Strength for Stanley
Team Callum
Team Dex
Team Felix
Team Oscar
Team Thomas
Together for Rhys
William's Fund

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WILLIAM'S FUND

ACTION FOR ARVIN | Duchenne UK

ACTION FOR ZACH

Archie's Army
Helping Fight Muscular Dystrophy

ARCHIE'S MARCH

BACKINGJACK
to help us beat Duchenne Muscular Dystrophy

Ben vs Duchenne

Please help us in
Changing Charlie's Future

CURE4GEORGE
Fighting Duchenne Muscular Dystrophy

DEFENDING WILLIAM AGAINST DMD

EDWARD
STEAM TEAM

Elliot's
Endeavour to
End Duchenne

FOR FELIX

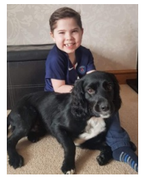
Fight for FINN

CHASING CONNOR'S CURE

HENRY'S HURDLES

CLIMBING FOR A CURE
HENRY'S HILLS

Duchenne UK
Help Harry



JACK'S AIM

JACKS MISSION

Jacobi's WISH

JOE'S JOURNEY
TO END DUCHENNE

LIFTING LOUIS

Love for Leon
Going the Distance to End Duchenne

MATTHEW'S
Mighty Mission
to end Duchenne

team Reilly

Moving Muscles For Marcus

MUSCLES FOR MITCHELL
strength through support
Fighting Duchenne Muscular Dystrophy

STRENGTH FOR STANLEY

TOGETHER for Rhys

Smile with Shiv
Fight Duchenne

RALPHY'S FUND

TEAM DEX
FUNDING RESEARCH INTO DMD

JJ'S
STONGER TOMORROW

HENRY'S MISSION
(to end Duchenne)

KAIRO'S KREW
Together we will kick Duchenne

ROWAN'S RAISERS
RISING ABOVE DUCHENNE

EZRA'S MISSION
TO END DUCHENNE

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