Duchenne UK

Turning Research into Reality: Innovation, Investment, Impact

IMPACT REPORT 2025





A message from our founders

A diagnosis of Duchenne Muscular Dystrophy (DMD) is devastating for families. The future you dreamt of for your child is stolen from you, to be replaced by gut-wrenching fear, anxiety, deep grief and loss. Duchenne UK is here to shine light into that dark and lonely place.

Leading with purpose
It's a place we once were, a place of darkness, isolation and vulnerability. But in thirteen years, Duchenne UK has helped to transform the landscape: to a point where, once there were no treatments, today we have two new approved treatments for DMD in the UK. We have a place where you can register your child to take part in clinical trials; a place where you can access our NICE (National Institute for Health and Care Excellence) recognised care guides to make sure your child gets the best care at every stage of the Duchenne journey; a place where research is actively happening here in the UK, a place where everything that CAN be done to accelerate research in the UK IS being done ... by Duchenne UK.

Founders' perspective: looking back, moving forward
Our approach is defined by four guiding principles: Disrupt, Innovate, Create and Accelerate:

Disrupt because developing drugs is hard in rare disease and there are challenges at every turn. When we come across one, we challenge: we disrupt.
Innovate and **create** because we come up with ideas and practical, deliverable solutions to change the landscape: And we IMPLEMENT those changes.
And **accelerate**, because Duchenne is a progressive disease and we don't have time on our side.

As you will see in this report, these driving principles are delivering tangible impact ... from creating the innovative Duchenne UK Virtual Hospital that will deliver the best standards of care for adults, to our innovative work in technology to help bring back the use of arms in young men with DMD. We have campaigned relentlessly to bring access to a new drug this year, and you can read about how we are successfully challenging the paradigm to make access for rare disease drugs fairer.

Leading in partnership
We work with pharmaceuticals and with biotechs, we work globally with leading academics and research teams. And here in the UK we are proud to work with the John Walton Muscular Dystrophy Research Centre (JWMDRC) to deliver two key programmes, our clinical trial network and care programme.

We've had an incredible year of engaging with regulators, with MPs and with government to ensure that our expertise in these areas, and your voices for new treatments and best care, are heard, are listened to and acted upon.

Duchenne UK is ensuring breakthroughs aren't just discovered - they reach families quickly and improve lives.

Looking back to when we started, there were no approved standards of care that were relevant to the UK healthcare system. Very few clinical trials were happening, and there were no approved treatments. The landscape today has changed beyond recognition, with multiple companies developing treatments for DMD across different modalities. But it's the work that Duchenne UK has done to ensure that the UK is a vibrant and flourishing place to do research which means that those companies are able to come to the UK, to recruit patients to their trials and run them.

The truth is that we have achieved so much this year that there wasn't space to include it all. So, we took the decision to focus on our biggest wins.

They represent only part of the story. So much more has happened thanks to the dedication of our community, families, researchers, clinicians, and supporters who make every breakthrough possible. Every project funded, every campaign led, and every conversation with policymakers has contributed to real progress for people living with Duchenne.

We are proud to showcase these achievements, knowing they reflect the collective effort of so many working together toward one goal: to improve lives now and find a cure for the future.

EMILY REUBEN OBE AND ALEX JOHNSON OBE

disrupt
create
innovate
accelerate

Our year at a glance

Thanks to your incredible support, we've had a remarkable year advancing Duchenne research and innovation with:

44
PROJECTS DELIVERED

£7.5 Million
TOTAL INVESTMENT

13
BRAND NEW PROJECTS

These projects included: Grants to **6 hospitals** and **10 universities,** pushing the boundaries of what's possible in Duchenne research, innovation and treatment.

£3.1 Million

Committed to in-house projects and grant funding, including pioneering work in gene editing therapy and the development of virtual hospitals.

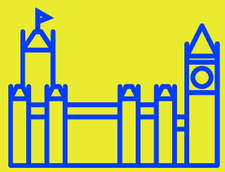
5

of these innovative projects are driven by our in-house team of engineers and specialists, including **Elevex and Stretch**, designed to improve quality of life and care.

The **Duchenne Dash 2025** was once again a testament to the power of community and determination

126
RIDERS TOOK PART

£959,815
RAISED



Through the **Time is Muscle campaign**, we took action with our community to advocate for access to crucial treatments, with **2 Drop-in events in parliament** attended by

35 MPs & Peers

actively engaged with our campaign.

By the end of 2025, we achieved:

20

NHS Trusts delivering the Early Access Programme (EAP) for givinostat, the first treatment shown to slow down progression of DMD in clinical trials.

More than

200

patients receiving givinostat.

At the same time, we were fighting for the medicine to be reimbursed and approved for use on the NHS to ensure everyone who could potentially benefit could access the treatment.

Working with the community, we delivered unprecedented engagement and influence during the NICE appraisal of givinostat with:

A **record**

120

observers attending the first NICE Committee meeting.

6

hours long extended second Committee meeting reflecting the depth of discussion.

We're also proud to have:

58

active Friends and Family Funds showing that grassroots support remains strong and fundamental to our mission.

Through **Duchenne Care UK** (formerly DMD Care UK), we launched:

5

new care guides for families and clinicians.

These provide trusted information on key areas such as steroids, bone health, psychosocial and respiratory care, as well as educational support. This means that we now have ten guides available.

Through the **Duchenne Hub UK** (formerly DMD Hub UK) we continued to accelerate the development of new treatments for Duchenne and created more opportunities for patients to take part in research and clinical trials.

6
clinical trials supported

5
new trials opened

26 patients referred to relevant trials at **4** of our hub sites in Leeds, London Great Ormond Street Hospital, Newcastle and Oxford.

Duchenne Care UK | Duchenne Hub UK | Duchenne UK | The John Walton Muscular Dystrophy Research Centre

From zero to 200: Driving access to givinostat nationwide

Accelerating access to treatment is at the heart of our mission to end Duchenne. At the start of 2025, despite Medicines and Healthcare products Regulatory Agency (MHRA) approval and givinostat being available free through the Early Access Programme (EAP), no patients were receiving it. Our Time is Muscle campaign changed that. By the end of the year, 20 of 24 NHS Trusts had started treatment for over 200 patients, with more preparing to roll out following NICE approval. Working alongside NICE, we secured full NHS funding for all eligible patients in December 2025, ensuring long-term access to this important therapy.

Emily and Alex celebrating first patient dosed with givinostat with the team at the Leicester Royal Infirmary.

Duchenne UK CEO, Emily Reuben OBE, meeting with CEO, senior leaders and clinicians at GOSH.

Action that delivered change

In January 2025, we united our patient community and brought families living with Duchenne to the heart of Parliament, giving them a powerful voice in front of their MPs. Parents shared their stories and the urgency of access to treatment, inspiring support from more than 35 MPs, including the Secretary of State for Health and Social Care, Rt Hon. Wes Streeting MP, who pledged to investigate the barriers standing in the way.

That commitment led to a follow-up meeting in March, where we learned the stark reality: decisions to join EAPs rest with each individual NHS Trust, leaving families facing uncertainty and delays. This pivotal moment strengthened our resolve and laid the foundation for the breakthroughs that followed later in the year.

Briefing Secretary of State for Health and Social Care, Rt Hon Wes Streeting MP on our Time is Muscle Campaign.

March 2025 marked a historic milestone when Leicester Royal Infirmary became the first site to dose a patient with givinostat outside of a clinical trial, a landmark day proving the EAP could be delivered. From that moment, our team worked tirelessly, travelling across England, Northern Ireland, Scotland, and Wales to meet NHS Trust leaders, clinicians, MPs, and government representatives, while supporting families campaigning for access.

A turning point came during a meeting at Great Ormond Street Hospital (GOSH), where our CEO, Emily Reuben, successfully changed the Trust's position on the EAP and secured their commitment to start treatment. This breakthrough sparked momentum, with other Trusts following GOSH's lead and accelerating access for hundreds of patients.

The power of patient advocacy

Strong cross-party support in Parliament, with MPs challenging the postcode lottery of access, kept pressure on the government to act. At the same time, we worked Trust by Trust to secure delivery of the EAP, backed by national and local media coverage exposing the injustice families faced. This growing momentum drove change. Bristol Children's Hospital began treatment in August, and by October hospitals across Birmingham were rolling out givinostat, bringing hope to many more families.

The success of our campaign was powered by the strength of our entire Duchenne community. Families, friends, and supporters came together, engaging political representatives, speaking to the media, and bravely sharing their stories, to turn advocacy into action and drive real change for everyone affected by Duchenne.

Alongside our Time is Muscle campaign, we worked closely with NICE to secure approval for givinostat so it could be funded for routine NHS use for all eligible patients. NICE began its assessment in early 2024, with Duchenne UK actively participating throughout. Despite numerous delays, we fought to ensure the process reflected the realities of Duchenne.

In July 2025, the medicine was finally reviewed by NICE's Highly Specialised Technology Committee. Our nominated patient experts, Alex Johnson, Duchenne UK co-founder, and Emma Hallam, founder of Alex's Wish, endured an intense and challenging session that exposed a fundamental lack of understanding of Duchenne and its devastating impact on families.

Cross-party MPs gathered outside parliament to show support for our #TimeisMuscle campaign.

Why lived experience matters

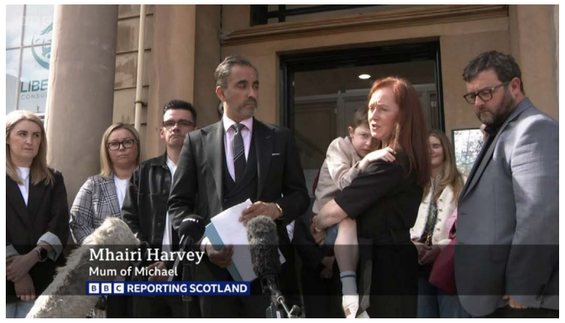
We raised serious concerns with NICE about the treatment of patient experts and the inaccurate portrayal of Duchenne. In August, when the Committee failed to reach a decision, a second call for evidence was launched, an enormous challenge over just four weeks during the summer holidays. Thanks to our groundbreaking Project HERCULES, we delivered a comprehensive, evidence-based dossier, including caregiver impact data, equality analysis, and lived experience insights.

By the October meeting, the tone had shifted dramatically, with a far better understanding of Duchenne and the value of a treatment that could slow progression. Our patient experts, Fleur Chandler and Dr John Hastie, powerfully conveyed the real-world impact and cost benefits of givinostat. In December, the appraisal was paused for commercial negotiations between the company and NHS England.

Also in December, the Scottish Medicines Consortium (SMC) accepted givinostat for use in NHS Scotland. This is a landmark decision for Scotland and testament to the tireless campaigning of families, patient representatives, and expert witnesses who helped make this possible.

Our Time is Muscle campaign was long and challenging, exposing systemic flaws in early access schemes and regulatory processes that left patients waiting and, in some cases, denied treatment. We are determined to change that. In October, we convened a policy roundtable to shape a better pathway for timely, equitable access.

In 2026, we will work with partners to pilot new approaches, advocate for reforms, and ensure regulatory systems are fit for purpose. We will also continue efforts to secure access including for non-ambulant patients and develop clinical guidance through Duchenne Care UK to support safe administration and management of side effects. Together, these steps will help create a future where every patient can access life-changing treatments without delay.



Scottish families speak to the media after meeting with Scottish Health Secretary, Neil Gray.

Families in Northern Ireland meeting with Mike Nesbitt MLA, Minister of Health.

Assistive technologies: Smarter, thoughtful design

“I hope Elevex will help me to maintain independence, support me to achieve what I want and build my confidence to continue doing all the things I enjoy such as music. It is a great opportunity to show what is possible to achieve with assistive technology despite living with Duchenne.”

- Benjamin James

Elevex - our upper arm support device championing user-led design.

Elevex: Mobility innovation

Elevex is a new arm-support device that we are developing for people with Duchenne. It’s made to be used while sitting in a wheelchair and helps users move their arms more easily as their muscles get weaker. Many people with Duchenne say losing arm movement is harder than losing the ability to walk, because we use our arms for so many daily tasks like eating, drinking, and talking.

Elevex works by boosting the user’s remaining muscle strength. It makes the arm feel lighter, like moving in water, so tasks feel easier and more natural.

In 2025, we focused on improving the mechanical design and making sure the controls feel smooth and natural. We worked with experts at the University of Central Lancashire to study how people move their arms during important tasks. This helped us design a lift system that balances the arm’s weight.

We started with a shoulder support prototype, since the shoulder is a complex joint. We also created a comfortable vest to hold the device. Later, we teamed up again with engineers at Frazer Nash Consultancy to build a lower arm support with a special elbow joint. By the end of the year, we had a full-size prototype that can be tested next to any wheelchair.

Testing and refining Elevex with the community.

Testing with people in the Duchenne community has been key. Their feedback helped us improve the design and plan the next steps. In 2026, we’ll focus on final testing, getting medical approvals, and preparing for production. We hope to launch Elevex in early 2027 to help people with Duchenne stay independent.

Stretch: An alternative to night splints

Stretch is a project to improve night splints and stretching routines for people with Duchenne. These are often recommended to help keep joints flexible, but many families say they’re uncomfortable and hard to stick with. Physiotherapists agree that current options don’t work well for everyone.

In early 2025, we started working on a prototype acquired from Solid Biosciences. We added a power pack and simple controls and showed it to physiotherapists at the New Horizons conference in March. Their feedback confirmed that better solutions are needed.

We then carried out detailed research, talking to physiotherapists, care managers, orthotists, parents, and people with Duchenne. We also observed families using splints and stretching routines. This gave us a clearer understanding of the problems and what people really need.

Developing new approaches for stretching and night splints.

In October, we used this research to guide the next phase of the project. We’re now deciding whether to improve the current prototype or design something different. Our goal is to create a device that’s comfortable, easy to use, and helps people stick with their stretching routines leading to better health and quality of life.

Transforming care, transforming lives

Through Duchenne Care UK, we continued to improve care for people with Duchenne across the UK. By developing new clinical guidelines and easy-to-use resources for families and healthcare professionals, the programme has helped to ensure better, more consistent care, wherever someone lives and whatever stage of Duchenne they're at.

Duchenne 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.

A growing library of support

Through family-friendly guides and practical resources, we give parents the confidence to advocate for their child's needs. Knowledge is power and we're putting that power in the hands of families. In 2025, we launched five new guides for families and clinicians:

Duchenne Care UK guides for families.

1. Physiotherapy and Occupational Therapy

A guide and clinical recommendations to help families understand what good therapy looks like and support professionals in delivering it.

2. Orthopaedic Care

Resources to help manage both emergency and planned interventions for fractures and contractures, with clear advice for families and clinicians.

3. Emergency Care

A guide to help families prepare for hospital visits and support emergency teams with key information, including the In Case of Emergency (ICE) app.

4. Corticosteroids

Guideline recommendations and Family Guide to explain the use of steroids and the benefits and risks. This covers prednisolone, deflazacort and vamorolone.

5. Psychosocial guideline recommendations

A resource that describes what best care looks like for the management of neurodiversity, behavioural and learning needs in Duchenne as well as emotional support and mental well-being. These recommendations target neuromuscular teams; mental health professionals; and educators and aim to support improvements in provision.

When givinostat became available through the UK EAP, Duchenne Care UK's Emerging Therapies working group developed and shared interim recommendations to ensure a consistent national approach and avoid delays in real-world use.

With ten family guides now available, Duchenne Care UK offers trusted information on key areas like steroids, bone health, and respiratory care. All resources are free and created with input from families and clinical experts.

Professor Michela Guglieri addressing the annual Duchenne Care UK meeting, bringing together clinicians and patient representatives.

Duchenne Care UK
BEST CARE FOR ALL
Duchenne UK | John Walton

Together we are driving change in care

By uniting clinicians, researchers, and families, we are rewriting the story of care for this generation. Duchenne Care UK will keep working to close gaps in care and support best practice across the UK.

We gained national recognition for the Cardiac and Respiratory Guidelines

On 6 September, ahead of World Duchenne Awareness Day, which takes place annually on 7 September, Duchenne Care UK's cardiac care guidelines were officially recognised (curated) by NICE. This is a major step forward in improving heart care for people with Duchenne. This recognition helps to ensure more consistent monitoring and treatment, which can lead to better long-term health outcomes. Since then, the project's respiratory care guidelines have also been assessed and recognised by NICE following the same process.

Mark Minchin, Associate Director at NICE, speaking about our collaboration at New Horizons.

> *"Guideline collaboration is a new programme within NICE designed to provide useful and useable guidance in an efficient and sustainable manner. As well as supporting working at pace, to get the best care to people quickly, it also enables us to share good practice, reduce and remove duplication, and avoid mixed messages through misaligned or conflicting guidance. Collaborating with key partners such as DMD Care UK will also help support implementation."*
>
> -Professor Jonathan Benger, NICE Chief Medical Officer and Deputy Chief Executive

Pioneering virtual care for adults living with Duchenne

We are proud to be driving a bold new approach to healthcare for adults living with Duchenne by funding a pioneering virtual care model that brings hospital-level support into people's homes.

The Duchenne UK Virtual Hospital responds directly to the growing needs of the adult Duchenne community. As more people live longer with Duchenne, their care becomes more complex. Yet adult services are often less coordinated and under greater pressure than paediatric care, leading to poorer outcomes and lower satisfaction.

Recognising this gap, we acted quickly. We saw the potential of virtual wards, highlighted in the 2024 Lord Darzi review, and moved to fund a solution tailored to the Duchenne community. The Duchenne UK Virtual Hospital uses technology to connect patients with a team of healthcare professionals, offering fast, joined-up care from home. While the NHS is exploring this model more broadly, it is not yet widely available for people with complex needs.

We partnered with leading experts in adult Duchenne care:

- Professor Ros Quinlivan (National Hospital for Neurology and Neurosurgery)
- Dr James Lilliker (Manchester Muscle Disease Unit)
- Professor Michela Guglieri (John Walton Muscular Dystrophy Research Centre)

Together, we developed a three-year project across London, Newcastle, and Manchester. The Duchenne UK Virtual Hospital will allow adults with Duchenne to access multiple specialist consultations from home, with professionals working as a single, coordinated team. It's designed to increase the frequency and quality of care, not replace face-to-face visits but enhance them.

The Duchenne UK Virtual Hospital also reflects our role in shaping national policy. The idea for a virtual hospital was first proposed by Professor Quinlivan during a Duchenne UK-hosted policy roundtable in Spring 2024. Since then, government announcements have echoed this vision, showing how our work is helping set the agenda and accelerate change.

By funding this initiative, we are demonstrating our ability to respond rapidly to both clinical insight and community need. We're not just supporting innovation, we're leading it. And we're committed to proving that virtual care can improve outcomes and experience for adults with Duchenne, while setting a precedent for wider NHS adoption.

> *"Similar models of care do not exist within the NHS. The time is right to develop a new sustainable model of care that is closer to home."*
>
> **- Professor Ros Quinlivan, National Hospital for Neurology and Neurosurgery**

Listening, learning, leading

Learning drives action. Every insight we gain helps shape smarter plans, sharper decisions, and more effective strategies bringing us closer to breakthroughs for people living with Duchenne. We need to stay curious, flexible, and ready to act fast. Research is constantly evolving, and when new data or opportunities arise, we move quickly, thanks to the funding that powers our work. It allows us to back promising ideas, shift gears when needed, keep momentum going and drive progress where it matters most. What we learn today shapes what we do tomorrow.

Our plans for 2026 are built on the latest research, insights from our community, and a deep understanding of where we can make the biggest impact. They include priorities that reflect what we've learned from the community ensuring our plans are grounded in real needs and future-focused solutions.

As life expectancy for people with Duchenne improves, care must evolve too. Many young people are let down during the transition from paediatric to adult NHS services, where adult care is often under-resourced and lacks dedicated commissioning. There's also a shortage of clinical studies focused on adults. To address this, in 2026 we're investing in the first **Duchenne UK Adult Hub**, which will include a research clinic to improve care and expand treatment options for adults living with Duchenne.

Managing Duchenne means juggling countless appointments, test results, letters, and making emergency plans, and keeping track of it all can be exhausting for families. Through the 2026 launch of **Duchenne UK Connect**, we will help them to keep health information in one place, making it easier to share details with healthcare professionals and to monitor the disease and tailor treatment. It will ensure the right care is given in emergencies, improve coordination between families and multidisciplinary teams, support communication with schools and social care providers, and simplify recruitment to clinical trials making care more connected, responsive, and effective.

The **Duchenne UK Institute for Assistive Technology** is the new name for our ongoing work to improve tools and devices that help disabled people live more independently. Building on the foundations of previous projects, we're continuing to unite charities, researchers, designers, and manufacturers to create products that truly meet the needs of people with disabilities. Our approach keeps disabled people at the heart of the design process, applying lessons learned from Elevex, the arm support device we developed, to deliver technology that works in real-life situations.

Our experience with givinostat exposed major flaws in the NHS health technology appraisal process. We are calling for listening exercises to become standard, ensuring patient and clinical insight informs decisions for complex, life-limiting paediatric conditions. Working with regulators, government, and patient groups, we aim to reform assessments so treatments like those for Duchenne are valued appropriately and reach patients faster. By learning from these challenges, we can create a fairer, faster system that delivers hope and life-changing therapies to every person who needs them.

Through the Duchenne Hub UK we will continue to actively engage with industry to help deliver more DMD clinical trials in the UK. In 2026, we will strengthen relationships, tools and resources to help companies effectively and efficiently plan trials and create more opportunities for patients to participate.

In 2026, we also plan to refresh our programmes by updating their names to offer greater clarity and alignment across all areas of our work.

Investing in impact

Every pound raised has been carefully allocated to maximise impact, accelerating breakthroughs and supporting families.

This year, our funding enabled us to drive progress in Duchenne research and advocacy.

Total Income

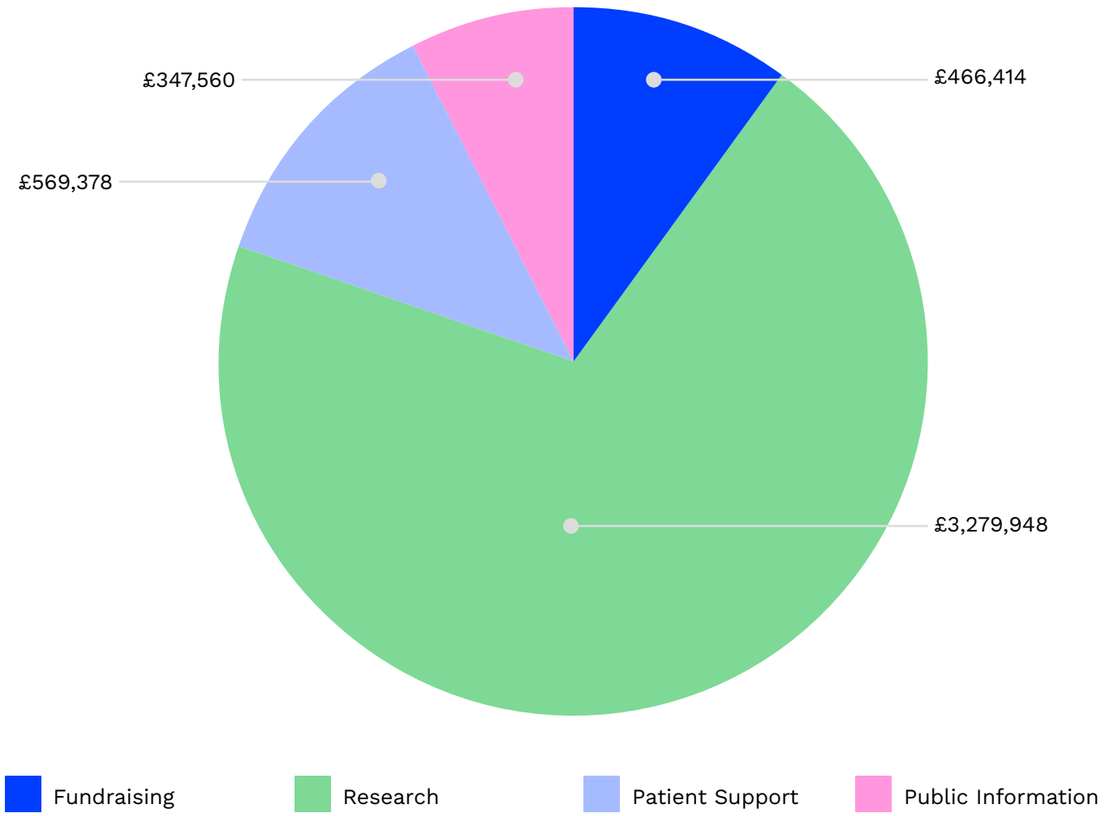
£3,913,524

Generated through grants, community fundraising, corporate support, and events such as the Duchenne Dash

Total Expenditure

£4,663,300

With the majority invested directly into research projects, in-house innovation, and patient support initiatives.



Together, we made this possible

It’s been an incredible year. Together, we are making an extraordinary impact. Every achievement has only been possible because of you, our donors, supporters, partners and dedicated community.

Your generosity has funded groundbreaking research and innovation, accelerated access to treatments, powered advocacy campaigns, and ensured families with DMD don’t feel so alone. Every gift, every fundraising challenge, and every act of kindness brings us closer to ending Duchenne.

When you give to us, you power a model unlike any other. No duplication, no wasted effort. We do it all: funding research, supporting families, and driving systemic change. Every pound accelerates breakthroughs and brings hope closer.

Thank you for your commitment to changing the world for everyone with DMD.

Charity Partners

Joining Jack • Alex's Wish • Duchenne Research Fund • Duchenne Now • Parent Project Muscular Dystrophy • The Duchenne Parent Project

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