



# ACTION DUCHENNE: DELIVERING HOPE & CHANGE IN 2024



## DUCHENNE

A rare, genetic, disabling, muscle wasting condition, diagnosed around the age of four. People living with the condition experience progressive muscle weakness, with a life expectancy around 30 years.

There is no cure to this day, but with better technology, awareness and improvement in the standards of care, people with Duchenne can live longer and more fulfilled lives.



## OUR MISSION

While we hope that research and clinical trials will one day lead to a treatment, or cure, for Duchenne, we believe it is vital to support families living with the condition today.

Action Duchenne aims to support every child, young person, adult and family throughout their Duchenne journey.

We call this All-through Support.



## OUR HISTORY

Founded in 2001, Action Duchenne is a UK charity that supports children, young people, adults, and families affected by Duchenne muscular dystrophy.

We work with the NHS to improve care, fund research into new treatments, and promote an inclusive society where disability is accepted, and differences are celebrated.

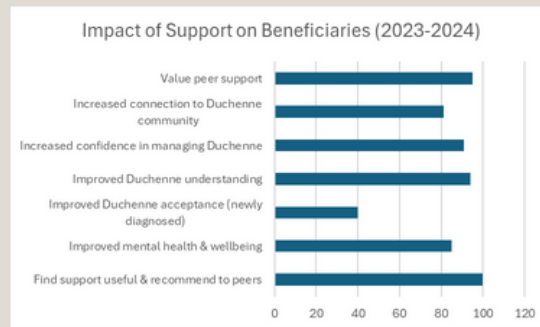


**Our vision : A world where lives are no longer limited by Duchenne muscular dystrophy**

# IMPACT OF SUPPORT ON BENEFICIARIES

In 2023-2024, we aim to:

- support **10%** more families
- grow our science education programmes
- engage with more schools and healthcare professionals.



“ I left the workshop feeling like I was part of a community ”

**885**

**beneficiaries supported so far in 2023-2024, an 11.5% increase from 2022-2023**

## IMPACT 2024

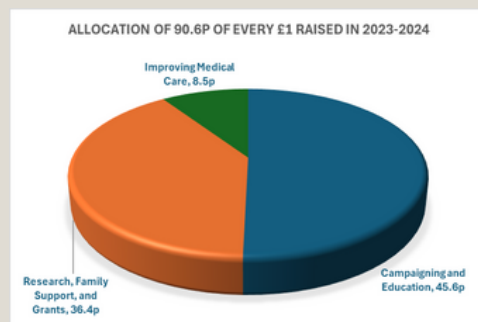
**In 2024, our aim is simple:**

to support and empower everyone affected by Duchenne muscular dystrophy. We are committed to advancing research, reaching more families, and providing the support they need. Together, we are making a real difference and giving hope to those who need it most

“ It was a hugely helpful day for us in clarifying a lot about our son’s potential future and reassuring us that there is more hope than we imagined ”

**90.6p of every £1 raised went to charitable activities, as shown in our audited accounts:**

- 45.6p on campaigning and education
- 36.4p on research, family support, and grants
- 8.5p on improving medical care and management for people with Duchenne



# HELPING FAMILIES MAKE INFORMED DECISIONS

**23** science education workshops delivered across the UK and Ireland  
**95%** of postcodes covered  
**48** science live, bite-sized videos developed



“ It was really useful to hear more, to get a better understanding and to meet others. It makes you feel less alone in this ”

**94%**

reported increased understanding of the condition

## SUPPORTING FAMILIES

“ A shoulder to cry on, and the chance to build friendship- friendships that matter so much when times are tough ”

**4** group counselling programmes delivered to **37** Duchenne parents and carers  
**6** School Duchenne Awareness Information events, reaching **87** professionals

**44**

group support meetings held

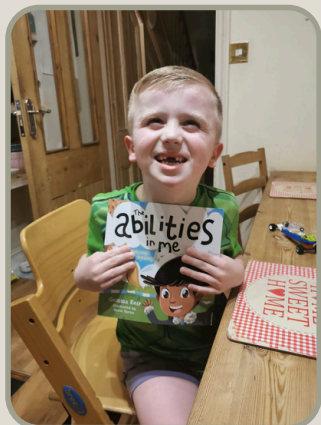


“ I didn't realise how much I need an outlet like that, it's the first time I've had the opportunity to openly talk about things ”





# SUPPORTING PARENTS THROUGH DIAGNOSIS



82

newly diagnosed families supported

“After speaking with Action Duchenne, I learned to take care of things I can change and focus on what we considered important”



7

Specialist hospital referral pathways established

## SUPPORTING YOUNG PEOPLE

20 professional-led online sessions delivered

4 virtual sessions for young people aged 8-14 & their parent/carers

“I want to tell my 10 year old self and all those boys living with Duchenne that anything is possible if you want it and that you can live your dreams”

16

young people participated in 3 residential weekends



## SUPPORT THROUGH END OF LIFE & BEREAVEMENT

104

views to end of life & bereavement webpage

“He knew he was loved for who he was and Duchenne didn't define him”

Survey conducted to inform the support needed  
Contact and sign-posting agreements made with partner organisations

# ACTION DUCHENNE CONFERENCE 2023

26

sessions with 32 speakers  
through 3 content streams

“Excellent content, fantastic speakers and well organised conference. I attended the conference last year and it changed my life forever”



323 Registrations  
Clinical expertise, cutting edge research and  
connection through lived experience

## THANK YOU

We want to thank all our funders, partner organisations, and supporters. Your generosity has allowed us to deliver vital projects, from supporting families to funding research and improving care.



## HOW CAN YOU HELP?

Help us create a future where Duchenne muscular dystrophy no longer limits lives. Whether it's by donating, volunteering or getting involved in our projects, together we can make a real difference to everyone affected by Duchenne.

Join us today: [www.actionduchenne.org](http://www.actionduchenne.org)