
ACTION DUCHENNE
About Duchenne muscular dystrophy
About Action Duchenne
Transition to Adulthood
For young people aged 14-25 years living with Duchenne.
Programmes combining residential weekend experiences alongside expert-led online sessions to empower, support and inspire.
Creating a platform for young people living with Duchenne to connect, share experiences and build friendships with others who face similar challenges.
"It's brilliant to be able to do things here that I can't do in everyday life"
Archie aged 19, Yes I Can Attendee
"Independence doesn't mean you have to live on your own, it means feeling able to do what you want to do"
Ravi Mehta,Transition to Adulthood Programme Lead
Transition to adulthood
info@actionduchenne.org
www.actionduchenne.org
07535498506
What is Turning Point?
TURNING POINT
BECOME A MEMBER
Support us to

2024 Annual General Meeting

5:30pm Tuesday 19 March

Via zoom

Agenda

Welcome – Gary Fegan, Trustee

CEO Report - Florence Boulton

Treasurer’s Report - Roger Cockerton

Ordinary Resolutions - Roger Cockerton

CEO’s Report - Florence Boulton

Key achievements in 2023

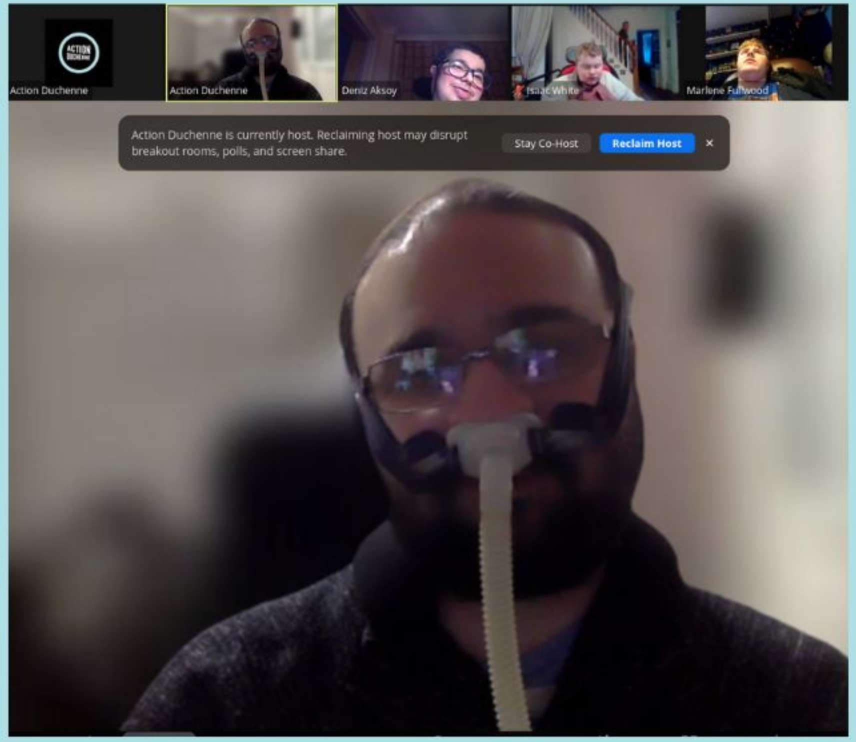
Action Duchenne Strategy 2024-2027

Plan and priorities for 2024/25

How to Stretch?

- Feel the muscle – is there any stretch/give
- Stretch SLOWLY
- Think about the normal range – don't try to get more
- Never cause pain as it will cause more problems

- Al ACTIVE or Active-Assisted



Action Duchenne is currently host. Reclaiming host may disrupt breakout rooms, polls, and screen share.

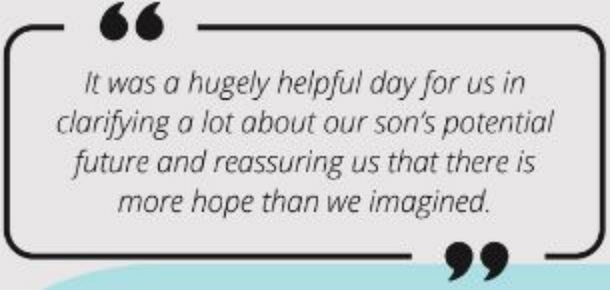
All-Through Support Programme

Achievements for 2023

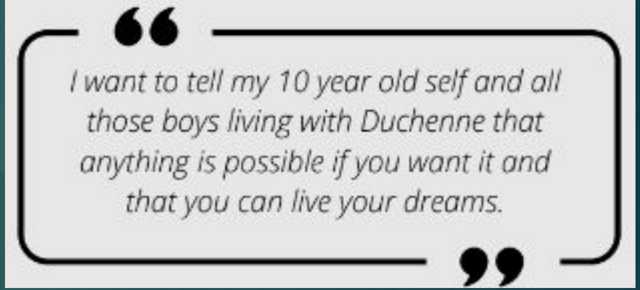
- 1625 support contacts made to 847 individuals
- 25 science education workshops delivered across the UK and Ireland
- 48 bitesize science videos
- 82 newly diagnosed families supported
- 64 young people aged 14-25 years participated in 2 ‘Yes I Can’ programmes
- 17 professional-led online sessions delivered
- 3 Group counselling programmes delivered for 20 individuals
- Dedicated website created with 104 views to end of life and bereavement webpages

Plans for 2024

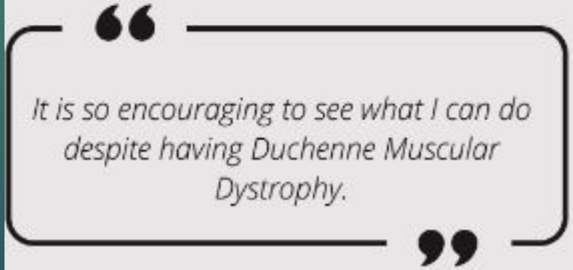
Supporting Parents Through Diagnosis
Helping Families Make Informed Decisions
Supporting Families
Supporting Young People Transitioning to Adulthood
Supporting End of Life and Bereavement



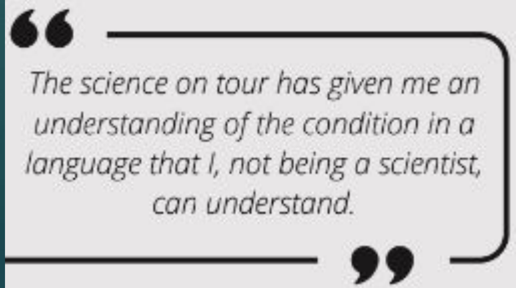
> *It was a hugely helpful day for us in clarifying a lot about our son’s potential future and reassuring us that there is more hope than we imagined.*



> *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.*



> *It is so encouraging to see what I can do despite having Duchenne Muscular Dystrophy.*



> *The science on tour has given me an understanding of the condition in a language that I, not being a scientist, can understand.*





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2023
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ACTION DUCHENNE
ACTION DUCHENNE
Empowering lives, searching for a cure

RANDOLPH & MORTIMER
THE INCOMPLETE TRUTH

Research and Campaign Projects

Achievements for 2023

Research -> Continuously seeking innovative and promising research directions

- Three research proposals reviewed in the 2022-2023. A key research strategy of Action Duchenne is supporting projects/research that facilitate standards of care.
- Together with MDUK, we are supporting a project which aims to develop standards of care for monitoring and management of bone health for adults with DMD.
- This project is undertaken by a group at Glasgow university and aims to enhance the Adult NorthStar Network guidelines and develop national standards of care of management of osteoporosis in adults with DMD. A common theme that has arisen from this project is to tackle the challenges of DXA scanning especially in non-ambulant adults.

Campaign Project -> Action Duchenne in collaboration with MDUK, families, clinicians, and patient groups campaigned for Translarna access, engaging in policy, parliamentary activities, and NICE meetings in the UK. Also, we supported European families after the EMA's negative decision.
Action Duchenne stands at the forefront of campaining for access to medicine by being a stakeholder in multiple appraisal in NICE. Since August 2023, Action Duchenne is supporting the following HTA appraisals: Vamorolone, Delandistrogene moxeparvovec, Givinostat (starting April 2024).

Plans for 2024

- Actively seek innovative and promising research directions to support by engaging with clinicians and researchers. The main focus will be on the standards of care to identify gaps and underinvestigated areas to improve the lives of individuals with Duchenne muscular dystrophy.
- Proactively engage with pharmaceutical companies, NIHR, NHS and NICE to support access of promising therapies for the Duchenne community.
- How to involve members: surveys, fundraising, be the voice of the community)

Action Duchenne International Conference

Achievements for 2023

- 323 Registrations with free tickets for those living with Duchenne and their families and £150 grant towards travel and accommodation costs
- 60+ expert speakers from around the world
- 26 sessions delivered through 3 parallel streams across 2 days
- Free creche service for 0-10yrs (39 bookings)
- Hangout area for 10-17yrs with opt in activities (26 bookings)
- Exhibitor area showcasing mobility equipment with equipment
- 250 attendees to the Friday dinner with 3 course meal, band and raffle
- Patron Harry Hill presented an AD Champion Awards to recognise our key supports

2024 International Conference: Fri 8th and Sat 9th Nov 2024
Register Your Interest now open

Action Duchenne Fundraising Strategy 2024-27

OUR PRIORITIES FOR THE COMING YEAR

- Significantly increase our grants income
- Grow our Community Fundraising
- Expand our membership
- Focus on High Value Opportunities
- Boost our Volunteer Support

Community Fundraising and Events

People organising their own events did incredibly well this year - raising over £100k. Walks and treks were a very popular way for our supporters to raise funds and awareness. For example, Lion House Dental Practice completed a 16 mile walk in 5 hours on the hottest day of the year so far! They were inspired by Levi, who lives with Duchenne and Levi and his mum Clare greeted them at the end of the walk.

In March 2023 the Action Duchenne Dinner Dance organised by Ruth Taylor and her amazing team was a huge success raising £54,528.58

Our first AD Champions Awards ceremony, presented by Patron Harry Hill at our conference this year, recognised the huge contribution that over 37 individuals made to enable us to continue our work.

RAF Falcon and Duchenne dad Sgt Doug McAll lifted the weight of a C130J Hercules, completing 344 deadlifts at 100kg in 53 minutes 17 seconds! He raised £1,046.51! The RAF Falcons also had us as a featured charity in their display brochure seen by audiences across the UK and Europe and held a special day at RAF Brize Norton for some of our Duchenne families.

Moorside Primary School had the amazing idea of combining their Holi celebrations with fundraising for Action Duchenne. Inspired by pupil Edward who lives with Duchenne, the school held a colour run to raise both money and awareness. Their moving story was featured on the BBC and we are so grateful to everyone involved.


ACTION DUCHENNE
18909
SEARCHING FOR A CURE


ACTION DUCHENNE


45765
ACTION DUCHENNE
44641


ACTION DUCHENNE


ACTION DUCHENNE
IMPROVING LIVES
SEARCHING FOR A CURE


LONDON CLASSICS
ACTION DUCHENNE
Improving lives. Searching for a cure.
tcs
Ford
RideLONDON ESSEX 100
Swim Serpentine

Treasurer's report - Roger Cockerton

Unrestricted reserves are £480k in March 2023 up from 420k in March 2022. The Unrestricted reserves exceed the minimum required by the Trustees that is based on three months of charity expenditure aimed at providing cover in the event of a sudden downturn in income, and to protect ongoing work programme.

In 2023 the Charity had a net surplus of £131k following a surplus of £202k in the previous year.

Income was £712k in 2023 - an increase of 26% on the previous year (£562k in 2022). This is mainly due an increase of 124% in income from charitable activities.

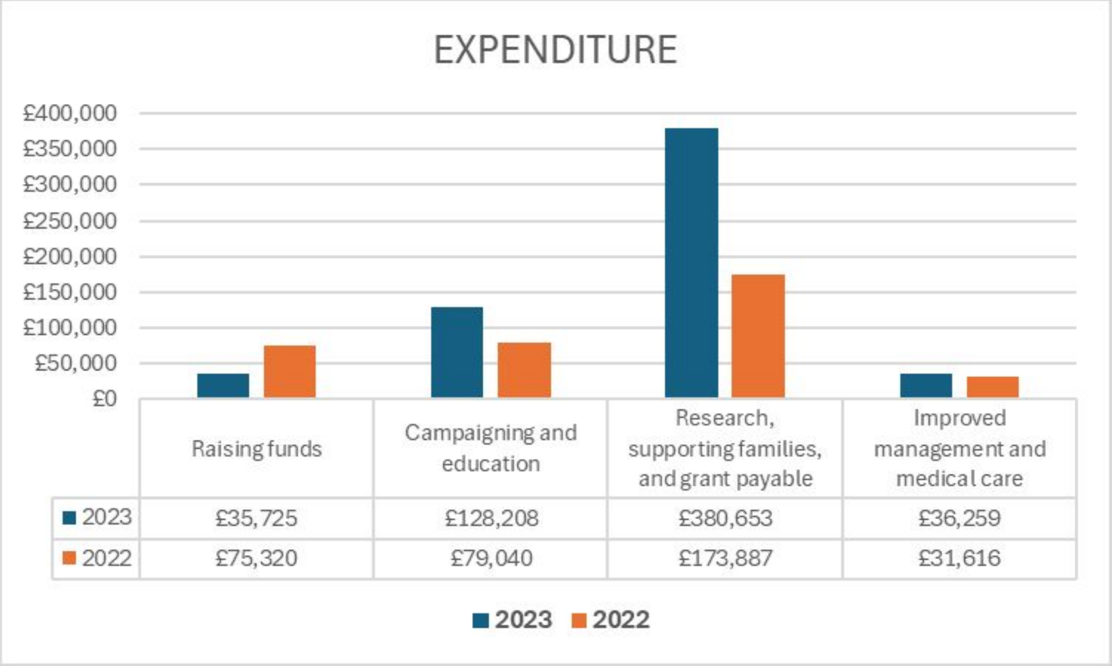
Expenditure on charitable activities was £545k in 2023 (2022: £285k), including allocated research, supporting families, grants payable, campaigning and education, and improved management and medical care costs. This represents 93.8% of total expenditure spent on charitable activities, compared to 79.1% in the previous year. Of this, £381k was spent on research, supporting families and grants payable (2022: £174k).

In 2023, the Charity repaid the Bounce Bank loan under the Coronavirus government-backed lending scheme in full.

The Charity's assets will be invested in accordance with the Trustees Act 2000 and the trust instrument. Any investments are managed prudently and in such a way as to provide sufficient income to enable the charity out its purposes effectively both in the short term and over the longer term.

Financial overview

	Donations and legacies	Charitiable activities - performance related grants	Other trading activities	Other income	TOTAL INCOME
■ 2023	£293,483	£257,442	£160,911	£28	£711,864
■ 2022	£347,160	£98,960	£114,795	£1,269	£562,186



	Raising funds	Campaigning and education	Research, supporting families, and grant payable	Improved management and medical care
■ 2023	£35,725	£128,208	£380,653	£36,259
■ 2022	£75,320	£79,040	£173,887	£31,616

We spend 93.8p in every £1 on, supporting families, scientific education, research and improved management and medical care.

£381k was spent on supporting families, research and grants payable.

Ordinary Resolutions - Roger Cockerton

1. To receive the accounts of the charity for the year ended 31 March 2023

2. To reappoint Mr Mark Silverman as trustee

3. To reappoint Mr Gary Fegan as trustee

4. To appoint Miss Emma Simmonds as trustee

4. To reappointment Simpson Wreford as auditor of the Charity

5. To authorise the trustees to set the auditor’s remuneration.

Bringing our whole community together

Bringing our Whole Community together

Our vision:	A world where lives are no longer limited by Duchenne muscular dystrophy.
Your support:	We can come together as a community to help more families in the UK and across the world.
Together:	We can help to improve the lives of thousands of young people and adults living with Duchenne.
Thank you!	Thanks to all of our generous supporters. You are the driving force behind the charity's success!

ACTION DUCHENNE

IMPROVING LIVES

SEARCHING FOR A CURE

THANK YOU!

Action Duchenne Charity Dinner Dance

REGENXBIO

Santander Foundation

SAREPTA THERAPEUTICS

PTC THERAPEUTICS

ACTION DUCHENNE

HM Government

In partnership with THE NATIONAL LOTTERY COMMUNITY FUND

contact For families with disabled children

Pears Foundation

HM Government

W

Garfield Weston FOUNDATION

ACTION DUCHENNE

Demelza

Pfizer

Lottery backs 'All-through Support' for Duchenne

JAGUAR

LAND ROVER

PepGen

WAVE LIFE SCIENCES

Treloar's Enabling Education

Edgewise THERAPEUTICS

Dyne THERAPEUTICS

Action Duchenne Annual International Conference

Action Duchenne receives peer-to-peer support grant

Child Bereavement UK

Sporting Bears Motor Club

santhera Pharmaceuticals

ITALFARMACO

Roche

Capricor

Paskin Children's Trust

Helping Children live the life they deserve

pathfinders neuromuscular alliance

GENETHON

SOLID BIOSCIENCES

MILLENNIUM POINT

ACCESS YOUR LIFE

ACHIEVE A BRIGHTER FUTURE

Action Duchenne receives funding for ground-breaking transition project