Action Duchenne Trustees

Candidate pack

September 2026

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CHARITY RECRUITMENT

ACTION DUCHENNE

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National Portfolio Organisation
Board Members

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ARTS COUNCIL ENGLAND

1 Introduction

Welcome from our Chair

I became Chair of the Charity in January 2025. By background, I am a retired GP and NHS Leader, and my grandson Sebastian has Duchenne Muscular Dystrophy.

You might wonder what Duchenne is?

"Your child has Duchenne Muscular Dystrophy". These are the words that almost 2 families a week will hear in the UK (100 diagnosed annually). Duchenne affects approximately 1 in every 3500 boys, with diagnosis between the ages of 3 and 5. As the condition progresses, boys will experience a decline in mobility, cardiac and respiratory complications and increasing care needs. The ability to walk is usually lost as a young teen, and a respirator required in early 20s. While the treatments for prolonging life are continuing to be developed, those living with Duchenne rarely live into their 30s. Furthermore, approximately half of boys living with Duchenne also live with complex neurodiversity such as ADHD and Autism. There is no cure.

Families living with Duchenne face numerous challenges. They must navigate complex health systems, education processes, housing adaptions and financial pressures. Parents also carry the burden of anticipatory grief and, due to the genetic component of Duchenne, carrier guilt. Siblings often play the role young carer, which too comes with an emotional strain.

Families often find themselves fighting a complex system, trying to give their child the best life they can, whilst neglecting their own mental health and wellbeing.

Whilst boys and young men living with Duchenne undoubtedly face huge challenges, with the right support, many are now able to work or volunteer, or live independently. At Action Duchenne, our focus is to support families to make the best decisions, to look after themselves and in doing so, enable the best quality of life for these young people.

1 Introduction

We stand apart from other organisations by offering community support throughout the Duchenne journey, including during bereavement. It would be fair to say the organisation has professionalised and stepped up its operational activity and governance in the last 12 months particularly. We proudly have a team of passionate, supportive staff who are keen to do more for families living with Duchenne, with many staff with direct lived experience.

Alongside our purpose, we have also reviewed and developed core values of supportive, empathetic, respectful, community focused and inclusive, which we proudly demonstrate in every interaction, decision and process, creating a space where people feel valued, heard and connected.

Why join us?

We want to expand and develop the Trustee Board to harness a wider set of skills, expertise and experience that will enrich the charity as we go forward. We have worked closely with the SLT over the last 12-18 months, and are now stepping back in to our governance roles and know more people will provide more value, more expertise and ultimately enable us go further.

It is an exciting time to join us, and to be part of something that makes a real and tangible difference.

We look forward to hearing from you.

Vicky

Vicky Pleydell

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About us

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2 About Us

Background and direction

Action Duchenne was originally set up by two parents who wanted to do something, like many do, when their son was diagnosed with Duchenne nearly 25 years ago.

Since then, the organisation has developed in to the support charity it is today. Action Duchenne has a clear purpose. We exist to support, empower and equip every DMD community in their journey from diagnosis and beyond. For over 20 years, we have been doing exactly that for thousands of families, but crucially, we don't do it alone.

Over recent years, with comprehensive partnerships with healthcare providers, other charities, local authorities, companies, research organisations and the community itself, we have established a unique service, placing Quality of Life, not searching for a cure, as our core focus. Furthermore, with lived experience at the heart of everything we do, we remain needs led with a constant listening ear to our community.

Our core activities involve bringing people together to share their experiences and learn from one another, increasing awareness of Duchenne, and bringing together families, Clinicians and pharmaceutical companies to increase understanding of the needs of those living with Duchenne. We provide support for families from the moment of diagnosis through their whole Duchenne journey.

Entirely funded through donations and charity grants, our services include:

- 1-2-1 support
- Supporting parents through diagnosis
- Group counselling
- Specific support groups such as 'Dads against Duchenne'
- Support at key transition stages
- Science communication and education
- End-of-life and bereavement services

> "From the first phone call, I felt completely understood and supported."
>
> **Duchenne Parent**

2 About Us

Impact and testimonials

My son Kiran is 16 years old and was diagnosed with Duchenne when he was 3. We first contacted Actiion Duchenne a few months later, at a loss to know how to cope with overwhelming feelings of grief and fear and feeling very isolated and alone. From that first phone call we were made to feel accepted and understood.

Throughout the last 13 years we have needed to rely on Action Duchenne for a range of information including access to information about new drug trials, to help with home adaptaptionsand finding the right electric wheelchair, but perhaps most important maing friendships with other families who just get it, in ways that our closest family and friends just can't.

Without that opportunity our experience and lives would have been so very different. We cannot thank Action Duchenne enough - it goes beyond words what they do for the Duchenne community.

The Rowntree family

We have built a friendship, a bond of support. We have people who understand how it feels. People we can talk freely with. Our journey is difficult; this makes it easier. The Action Duchenne team, new friends and support bubble give me hope.

Duchenne Parent

The level of support we have received from Action Duchenne has been crucial to our journey; it has been invaluable and a real lifeline. This support is fundamental to families living with Duchenne.

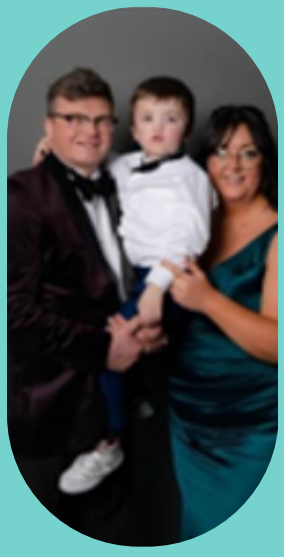
Duchenne Parent who accessed group counselling

2 About Us

Impact and testimonials

My son, Max, was diagnosed with Duchenne muscular dystrophy on 14th January 2020, when he was only 18 months old. To use the word devastated does not do justice in explaining how this affected me and my family. Fear, panic, and devastation spread across everyone we knew, in a domino motion of pain.
As Duchenne muscular dystrophy is such a rare condition, one of the biggest challenges we faced was explaining what the condition was, and how it will affect our Maxy in the future, before ending with 'there is no cure'. There were so many difficult conversations, tears, and stunned silence.

Action Duchenne has provided a vital supported to me and family since February 2020. Their help and knowledge of the condition has been nothing short of amazing.



Over the last few years we have approached other charities, be it for specific seminars or funding support. After spending time with them it was clear that they mainly focused on fundraising for a cure. Action Duchenne is different. They mainly focus on the family support throughout the whole journey, from diagnosis to the last day. They do not falter, instead they step forward on the hard days and remain a constant in our lives.

This project will help Action Duchenne continue and expand on the valuable work that is has been undertaking. I speak on behalf of all the families affected – and those who will be diagnosed in the weeks, months, and years ahead – when I ask you to support their wonderful and much-needed work helping those affected by this terrible condition.

Ruth Taylor, Duchenne Parent

2 About Us

Why join Action Duchenne as a Trustee?

Joining Action Duchenne as a trustee is an opportunity to create meaningful change where it is urgently needed, alongside families whose lives are shaped every day by Duchenne Muscular Dystrophy.

Action Duchenne sits at the heart of a fast moving, high impact space where decisions shape real lives. As a trustee you won't be advising from the sidelines, you 'll help steer the organisation that families trust, professionals respect and the Duchenne community relies on.

You don't need to be a Duchenne expert. You do need curiosity, sound judgement and a willingness to ask challenging questions in service of something bigger. Whether your background is governance, finance, law or communications, your perspective matters. This a role for people who want purpose with their governance.

If you are looking for a trustee role that is active, meaningful and impactful, join Action Duchenne. As part of strengthening our Board governance and assurance, we are seeking trustees who can bring professional expertise, independent challenge and robust oversight. This is an opportunity to help strengthen safeguarding assurance, financial stewardship, risk scrutiny and accountability across the organisation.

Your decisions will help shape better lives, stronger voices and a more hopeful future for individuals and families affected by Duchenne muscular dystrophy.

> For me, being a trustee means using my experience and judgement to help an organisation make good decisions in support of its mission. It is rewarding because the role combines purpose, challenge and responsibility: you contribute strategically, learn from committed colleagues, and help ensure the charity is well governed and focused on real impact. I would encourage anyone who wants to make a meaningful contribution to consider becoming a trustee.
>
> **Greg Hill, Trustee since 2014**

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About Us

Strengthening our Board

Action Duchenne is entering an important period of development, with a renewed strategy, growing programmes, new staff capacity and increasing governance demands. As part of this, we are strengthening the Trustee Board so that it has the right mix of skills, independence, lived understanding and professional expertise to provide effective oversight.

Trustees at Action Duchenne are not only ambassadors for the charity. They are responsible for asking good questions, testing assurance, scrutinising risk, overseeing safeguarding and financial controls, and ensuring that delegated authority is clear and accountable.

This recruitment round is informed by the Board's current skills and capacity needs. We are particularly interested in people who can help strengthen governance, finance, safeguarding assurance, HR/legal, fundraising, service delivery, risk management and strategic oversight.

Lived experience / diversity

The Board already has strong lived-experience representation, and now needs to strengthen balance, objectivity and independent external perspective.

We are also developing a Community Advisory Group so that people with lived experience can continue to shape our work in a structured and ongoing way. If you are interested in contributing through this route, please contact us at hr@actionduchenne.org for a conversation.

If there is a reason relating to accessibility or diversity in which you feel you can't apply for this role, please contact us for a conversation before making your application.

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Role description

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Role description

Trustee role

The Trustee role at any organisation is crucial, right now at Action Duchenne it is an exciting and dynamic time to be in the role as we finalise our strategy. You will use your expertise and experience to be involved in shaping our future and deepening our impact.

The Trustees provide oversight, ensure legal compliance and have check ins with the Chair and CEO on a regular basis. For us, being a Board member means being present, engaged and an ambassador for the organisation. Board members are each expected to actively participate in quarterly meetings, and in turn are expected to dedicate sufficient time to the role.

The Trustees appointed will become Directors of the Company limited by guarantee (no. 04899036) and a Trustee of the registered charity (no. 1101971), and therefore need to be eligible to take on these roles.

All Trustees must:

- Ensure that the charity is carrying out its purpose for the public benefit
- Comply with governing documents and the law
- Act in the charity's best interests
- Manage the charity's resources responsibly
- Act with reasonable care and skill, and
- Ensure the charity is accountable.
- Maintain Board-level oversight of safeguarding, ensuring appropriate scrutiny and assurance that safeguarding responsibilities, policies and procedures are effective, compliant and regularly reviewed.

The Trustee role is voluntary and unpaid, but reasonable travel expenses will be met.

The majority of formal meetings are conducted remotely through emails and conference calls, with quarterly away days in person in London.

We would welcome first time Trustees, and there will be a thorough induction and introduction to the team and the role. We are committed to Trustee development and training, and we have Trustee insurance for all Trustees.

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Role description

Time commitment

The Trustees currently meet quarterly. For each meeting, there is an expectation of pre-reading and preparation, and where there is appropriate expertise, Trustees can advise on their anticipated standards relating to areas of work (finance, service delivery, fundraising, HR, for example).

The anticipated time commitment is likely to be 8 hours a month, with the quarterly away days in addition to this. Trustees are expected to respond to emails within a week, and attend at least 75% of Board meetings.

A trial period of six months is offered, to ensure the fit works for both the new Trustee and the Board, and a maximum term of three years, with the opportunity to be re-elected once, to serve for a total of two terms - six years.

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Person specification

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4 Person spec

Essential criteria

Applicants must clearly demonstrate:

- An alignment with the Charity's values
- A strong commitment to the holistic approach of support
- Relevant skills and experience drawn from a professional background
- A willingness to devote time to the governance of Action Duchenne, including preparing for and attending Board meetings and Away Days
- Emotional intelligence to understand the physical, mental, social and emotional challenges facing those living with Duchenne
- An understanding and acceptance of legal duties, responsibilities and liabilities associated with trusteeship, or the willingness and ability to acquire this
- Strong independent judgement and the ability to constructively challenge ideas on the Board and with the CEO
- Proven ability to work creatively and strategically
- Strong communication and analytical skills

Skills

Action Duchenne is seeking to strengthen the Trustee Board in line with its current skills and capacity needs. We welcome applicants who can bring one or more of the following areas of expertise:

- finance, reserves, audit or charity financial control
- fundraising, income generation or grant accountability
- impact measurement or community support
- communications, public affairs or stakeholder engagement

We are also interested in applicants with broader experience who can bring independent judgement, constructive challenge and a strong commitment to accountability.

5 How to apply

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How to apply

Action Duchenne are working exclusively with Charisma Charity Recruitment.

Expressions of interest should be submitted through the Charisma website and include:

- A comprehensive CV
- A supporting statement (no more than two pages) noting why you would like to be a Trustee of Action Duchenne, how you align with the Charity, and what you feel you can give to the organisation

For an informal and confidential discussion about the role, please contact:
Sandra Smith, Senior Consultant at Charisma Charity Recruitment on 01962 813300 or email info@charismarecruitment.co.uk.

Charisma welcome and encourage expressions of interest from people of all backgrounds. We do not discriminate on the basis of disability, race, colour, ethnicity, gender, religion, sexual orientation, age, veteran status or other category protected by law.

Closing date: 4 November 2026

Interviews with Action Duchenne:

- **1st stage interviews will be held w/c 16 November**
- **2nd stage interviews will be held w/c 23 November**

Charisma vetting interviews must be completed by 6 November prior to shortlist submission on 9 November.

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