



Action Duchenne: Pharmaceutical and Biotechnology companies Funding Policy

1. Purpose and Scope

Action Duchenne is a UK charity that exists to support, empower and equip everyone affected by Duchenne muscular dystrophy (DMD). We work collaboratively with a wide range of stakeholders, including pharmaceutical companies, to ensure the best possible support for families.

This policy sets out how Action Duchenne will manage actual, potential and perceived conflicts or vested interests arising from funding or partnerships with pharmaceutical companies that research, develop or sell treatments for Duchenne muscular dystrophy. It applies to all trustees, staff, volunteers, and representatives of Action Duchenne, and covers all interactions, including sponsorship, donations, events, research partnerships, and advocacy activity.

2. Guiding Principles

Action Duchenne is committed to:

- **Independence:** Maintaining full control over our strategic priorities, policy positions, and communications.
- **Transparency:** Disclosing all pharmaceutical funding, including the value, purpose, and duration of support.
- **Integrity:** Ensuring that funding does not influence, or appear to influence, our decision-making, research, or advocacy.
- **Fairness and Equality:** Treating all companies equitably and avoiding preferential treatment based on funding level or relationship.
- **Compliance:** Adhering to the **Fundraising Regulator's Code of Fundraising Practice** and the **ABPI Code of Practice**, as well as UK charity law and the Nolan Principles of Public Life.

3. Managing Conflicts or vested interest

3.1 Definition

A conflict of interest arises when a trustee, staff member, volunteer, or the charity itself has, or appears to have, competing loyalties between the charity's mission and a pharmaceutical company's commercial interests.

3.2 Identification

Conflicts may arise when:

- A pharmaceutical company funds or sponsors Action Duchenne's activities (e.g. events, publications, campaigns).
- An individual associated with Action Duchenne holds shares, employment, or consultancy with a company involved in Duchenne research.
Advocacy or policy positions could directly affect the commercial interests of a funder.

3.3 Declaration

- All trustees and staff must declare any actual or potential conflicts annually and when they arise.
- The Chief Executive Officer will maintain a **Conflict-of-Interest Register**, reviewed quarterly
- Conflicts will be declared at the start of any meeting or discussion where they are relevant.
- It will be considered a conflict if a family member or close relation of a Trustee or staff member is in receipt of a specific treatment where this is considered to have a potential impact on decision making or objectivity.

3.4 Management

- Where a conflict exists, the individual will recuse themselves from related decision-making.
- Where organisational conflicts are identified, mitigations will be agreed and documented.
- All decisions relating to pharmaceutical funding will be approved by the Chief Executive Officer and reported to the Board.

4. Accepting Pharmaceutical Funding

4.1 Criteria for Acceptance

Action Duchenne may accept funding from pharmaceutical companies where:

- It aligns with our charitable objectives and benefits the Duchenne community.
- It does not compromise, or appear to compromise, our independence or reputation.
- It is provided without conditions influencing the charity's policy, research, or communications.

4.2 Due Diligence

Prior to acceptance, all potential pharmaceutical funding must undergo due diligence undertaken by the Head of Fundraising & Communications and Chief Scientific Officer, including:

- Review of the company's compliance record with the **ABPI Code of Practice** and relevant international standards.
- Assessment of potential reputational risks.
- Consideration of public perception and the impact on our beneficiaries.

A written **Funding Agreement** will be required, outlining:

- The purpose and amount of funding.
- Use of logos, brand placement, and acknowledgements.
- Confirmation that funding does not grant editorial control or influence.

4.3 Transparency and Disclosure

- All pharmaceutical funding above £1,000 will be listed annually on the Action Duchenne website, detailing the donor, amount, and purpose.
- Pharmaceutical support for specific events or campaigns will be clearly stated in materials and communications.

- The total proportion of Action Duchenne’s income derived from pharmaceutical companies will be reported in the Annual Report.

5. Partnership Conduct and Independence

- Action Duchenne will maintain a “**critical friend**” role — open to collaboration but prepared to challenge where necessary in the interests of patients and families.
- No company will be granted exclusivity over communication channels, patient access, or brand positioning.
- Patient information resources will remain independent and evidence-based, with content reviewed by our Science Team or an independent clinical expert.
- Where Action Duchenne sits on advisory panels or consults with pharmaceutical companies, this will be done transparently, and participation will not constitute endorsement of a specific product.

6. Governance and Oversight

- The Board of Trustees retains ultimate responsibility for ensuring that all funding relationships comply with this policy.
- The SLT will review:
 - All pharmaceutical income annually.
 - The Conflict-of-Interest Register.
 - Any complaints or public concerns regarding independence.
- The Chief Executive Officer will report annually to the Board on pharmaceutical relationships and their management.

7. Non-Compliance and Breaches

- Any breach or concern relating to this policy must be reported immediately to the Chief Executive Officer or Chair of Trustees.
- Breaches will be investigated and may result in disciplinary action, termination of agreements, or public clarification statements.

8. References

- **Fundraising Regulator’s Code of Fundraising Practice** – Sections 1.2 (Legal Compliance), 2.6 (Acceptance and Refusal of Donations), 2.7 (Transparency).
- **ABPI Code of Practice (2024)** – Clauses 29.1 on Transparency and Disclosure and clause 27 on relationships with Patient Organisations. **Charity Commission Guidance: CC20 – Charity Fundraising: A Guide to Trustee Duties.**
- **Nolan Principles of Public Life.**

9. Review

This policy will be reviewed every two years, or sooner if:

- There are significant changes to ABPI or Fundraising Regulator guidance; or
- The proportion of pharmaceutical funding to total income changes materially.

Policy Owner: Chief Executive Officer

Approved by: Action Duchenne Board of Trustees

Date approved: 21 January 2026

Date of next review: January 2028