



Join us to end Duchenne

Candidate Information Pack Finance and Resources Manager

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For background information on Duchenne UK please go to

www.duchenneuk.org

Candidate Background Briefing

JOIN US TO END DUCHENNE IN TEN

Why Join Us?

Would you like to play an integral role in our ground-breaking work to eradicate Duchenne Muscular Dystrophy in ten years? Duchenne UK is working with great energy and passion towards its goal and we now need someone who can help us to steer the organisation by providing strategic financial expertise and ensure that we are making the best use of all of our resources. It's a hugely exciting journey and requires a real team player who would thrive on ensuring that our organisation is strong and robust enough to keep our momentum going in order that that we meet our goal.

What is Duchenne Muscular Dystrophy?

Duchenne Muscular Dystrophy (DMD) is a devastating muscle-wasting disease and is the most common fatal genetic disease diagnosed in childhood. Children diagnosed with DMD are paralysed by their teens and won't usually live beyond their 20s.

About Duchenne UK

Duchenne UK is a lean, ambitious and highly focused charity with a clear vision: to fund and accelerate treatments and a cure for DMD, and to do so in a decade. We do this by identifying the very best projects from around the world with the highest chance of success, using our internationally respected Scientific Advisory Board. Duchenne UK is often an investor and initiator of projects that attract investment from other charities and funders. For example, in 2014 we invested \$1.7m in Solid Biosciences to help them create pre-clinical data for a gene therapy trial; this proved that the treatment had potential, which then attracted a further \$42m from commercial investors. A resulting trial on boys with DMD is on target to enter the clinic this year.

Our achievements

Duchenne UK was set up 5 years ago and was initially called the Duchenne Children's Trust. The charity was re-named Duchenne UK in 2016. It has achieved a huge amount in 5 years: amongst the many things we are proud of are:

- We are a dynamic, parent-led charity
- We have raised £5.5 million in 5 years
- £5 million has been spent and committed to research
- 90% of all money raised is spent directly on research

How do we fund this?

We have a number of keen and committed supporters and most of our funding comes through events, such as:

- The Duchenne Dash, an iconic VIP bike ride from London to Paris which raised £1m last year;

- A day of Touch Rugby, hosted by Owen and Andy Farrell;
- A Triathlon at Eton Dorney;
- We have a number of dedicated and committed fundraisers from within the DMD community who fundraise to support the research we fund.
- We are proud to partner with two other parent charities, Joining Jack and Alex's Wish, both of whom fundraise for research projects run by Duchenne UK.

Our Team

The team is both office- and project-based. There is an office in London, where this post will be based, with five team members, and an office in Wigan with a team of three. The organisation of the Duchenne Dash, as well as lobbying and marketing, are outsourced. There are also four internal advisory boards. See the organisation chart on the next page.

The Finance and Resources Manager

Building on our success we are now looking for an exceptional person who can join us and help us to achieve our goal of eradicating DMD within 10 years. This is a unique opportunity to have an impact on the future of our ground-breaking work. Whilst having financial and organisational skills is important, more important is a passion for our work; the ability to join a small, dynamic group of people and the creativity to contribute to our strategic planning and add value, helping us to plan and use our resources in a way that maximises our impact.

ORGANISATIONAL CHART FOR DUCHENNE UK showing roles and projects funded by the charity

LONDON OFFICE

Emily Crossley, Co-CEO/Founder
David Bull, Director of Research
Naomi Litchfield, Director of Patient
Engagement and Clinical Care
Molly Hunt, Communications

WIGAN OFFICE

Alex Johnson, Co-CEO/Founder
Melanie Whitehead, Senior
Fundraising & Events Co-ordinator
Nicola Tomkins, Fundraising &
Events

INTERNAL BOARDS

Patient Advisory Board
Scientific Advisory Board
Board of Trustees
Donor Advisory Board

DUCHENNE DASH

Emily Waring, Fundraising

COMMUNICATIONS, LOBBYING & MARKETING

Jessica Devenport, MHP
Archie Tollast, WCRS

DUK-FUNDED PROJECTS & STAFF

TAMOXIFEN

Fiona Lawrence, project manager for DUK
Daniela Rubino-Nacht, project manager in Switzerland

PROJECT HERCULES

Josie Godfrey
Zuzanna Bates
+ 5 Pharma Industry partners

THE HUB (NEWCASTLE)

Emma Heslop
Cathy Turner

50 RESEARCH PROJECTS CURRENTLY FUNDED

Job Description

| | |
|-------------------------|--|
| Job Title: | Finance and Resources Manager |
| Responsible to: | The Director and Trustees |
| Responsible for: | The Administrator |
| Hours: | 4–5 days per week ¹ |
| Holiday: | 25 working days a year plus bank holidays |
| Salary: | Circa £35–40,000 per year |

Purpose

- To be a key member of the Duchenne team responsible for strategic development and delivery of the organisation's aims and objectives.
- To provide advice and information on resource management to the Trustees, the Director and other team members.

Key Areas of Responsibility

Strategic planning, delivery and leadership

- Work closely with the team of trustees and staff to achieve the goal of eradicating DMD, contributing strategic, planning and financial skills.
- Support the Director's accountability to Trustees, having responsibility for resources and reporting on financial matters and risk.
- Support the organisation in strategy and planning; financial management; grants management and income generation.
- Lead and manage the Administrator, maximising their strengths and ensuring that they can contribute effectively.

Financial leadership and management

- Provide sound financial information and management, including: overseeing the management of the annual accounting, audit and budget processes; preparing financial reports; preparing statutory accounts in accordance with the Charity SORP; managing the year-end audit process and maintaining financial and other resources information.
- Ensure financial controls operate in line with policies and procedures.
- Support the income generation activities by advising on strategic financial planning and preparing budgets and forecasts for proposals, events and projects, etc.

¹ The number of days per week is open to negotiation. As this is a new role and if the successful candidate preferred to work part-time, then some of the non-financial management functions could be delegated to the Administrator role.

- Prepare and monitor budgets for the organisation generally.
- Manage non-research based contracts and support research project managers in financial matters.
- Ensure key risks are identified and managed and that the organisation is compliant with all relevant legislation: HMRC, Companies House and the Charity Commission.
- Prepare monthly management accounts and financial reports for donors.
- Manage the process of securing appropriate insurance for the charity annually.
- Support the Administrator in processing payroll and pension contributions and processing monthly payments.

Grant Management

- Create and maintain schedule of reports & other milestones from all our projects.
- Create and maintain schedule of grant payments to be made to all our projects.
- Liaise with other charities on joint projects, ensuring that financial and governance matters are dealt with.
- Manage reporting deadlines to trusts and donors, ensuring that they have helpful and accurate information.

Human Resources, IT and Health and Safety

- With support from external advisors and working with the Administrator, oversee the Charity's HR, IT and Health and Safety policies and practices.
- Oversee the administration of the payroll, ensuring that policies on pensions, sickness, parental leave, etc. are adhered to accurately.
- Keep up to date with changes in HR best practice and law and oversee the Administrator to ensure that HR manuals are updated.
- Schedule and ensure that annual staff performance reviews are carried out.
- Support the CEO and Trustees to deliver effective IT management.

Governance and Committees

- Work closely with the Trustees, managing the pattern of meetings and advising and enabling them to fulfil their duties.
- Present information and reports at meetings.
- Work with all relevant advisors, including auditors; lawyers; pension trustee and scheme employers; investment managers, etc.
- Manage the annual report process, ensuring that it is professionally and accurately produced.

Other

- Undertake any other relevant tasks in relation to the work of Duchenne UK as requested by the Director.

Other Terms and Conditions

Probation: The appointment is subject to an initial six-month period of probation, during which performance will be regularly reviewed. The hours worked can be flexible by agreement with the Director. On completion of the probationary period, notice will be three months on either side.

Pension: To be determined in accordance with government regulation

Location: West London. We are currently based in White City but will need to relocate to another office in West London over the coming year.

Finance and Resources Manager

Person Specification

| Qualifications, Experience and Skills | Essential | Desirable |
|--|------------------|------------------|
| A recognised accounting qualification, or qualification by experience | ✓ | |
| Substantial experience of financial and accounting matters | ✓ | |
| A minimum of three years' experience in the review and production of accounts up to final accounts stage | ✓ | |
| Experience of managing and reporting on complex budgets | ✓ | |
| Knowledge and understanding of PAYE | ✓ | |
| Experience of dealing with auditors | ✓ | |
| Excellent communication skills, including drafting and presenting reports | ✓ | |
| Experience of managing a varied work load to tight deadlines | ✓ | |
| Excellent IT skills including databases | ✓ | |
| Experience of overseeing HR, H&S and IT | | ✓ |
| People-management experience | | ✓ |
| Familiarity with charity/not-for-profit accounting requirements | ✓ | |
| Abilities and Aptitudes | | |
| An ability to foresee problems and design solutions | ✓ | |
| Flexible, with an ability and a readiness to develop interests in particular areas of work as the Foundation's priorities change | ✓ | |
| An understanding of and a commitment to issues of diversity and EO | ✓ | |
| Personal Qualities | | |
| Resilient and emotionally intelligent | ✓ | |
| A commitment to the aims of Duchenne UK | ✓ | |
| A team player who enjoys working in a small team | ✓ | |

The Recruitment Process

Timetable

| | |
|--|-------------------------|
| Deadline for applications | 1 December |
| Screening Interviews | 5 and 7 December |
| Candidate Assessment at Duchenne UK ² | 14 December |
| Final Interview (if required) | 18 December |
| Decision made and successful candidate notified | 20 December |

To Apply

If you would like to apply for this role, please complete the Application Form (download from <http://www.allysondavies-consultant.com/job-board/finance-and-resources-manager-duchenne-uk/>), and attach your CV outlining your career to date plus any academic and professional qualifications.

Please email these two documents, by 10am, on **Friday 1 December**, to duchenne@allysondavies-consultant.com

Information

If you require any further information or you would like to discuss anything in more detail, please contact Allyson at the above email address, or call 020 7828 3855 or 07968 556 164.

² This process will take 2.5 hours max in total. Candidates will not be expected to attend for the whole day.