



LAM Action Charity Co-ordinator

**Candidate pack
April 2026**



charisma
CHARITY RECRUITMENT

LAM ACTION
Supporting women with
Lymphangioleiomyomatosis





About us

About LAM Action

LAM Action is the UK charity for those with LAM, their families and doctors caring for them

LAM Action provides valuable support to those with LAM and their families and helps fund important research into LAM. As a small charity focused on an extremely rare disease, we are run almost exclusively by volunteers and generate almost all of our income from donations and fundraising. Although independent from the [NHS National Centre for LAM](#), we have close links to the medical and research staff there.

Our Mission

- Provides support, information and encouragement to those with LAM and their families.
- Helps educate health professionals about LAM and advance research into LAM.
- Raises funds to drive these activities.

Our Vision

Use of the drug [sirolimus](#) has had a very positive impact on the progression of LAM for many women, and quality of life, severity of symptoms and survival rates have improved as a result. However, sirolimus is not a cure for LAM. We aim to continue supporting people affected by LAM and funding research that may lead to additional treatments and an eventual cure for the disease.

Job description



Charity Co-ordinator

Hours	Hours: Part time – 12 hours per week, with Wednesdays as a set day
Salary	Salary: £39,000 pro rata
Location	Location: Remote, UK based

Main roles and responsibilities

Patient support

- Giving appropriate care and attention to people in distress
- Organising one-to-one and other support
- Liaising with regional and similar group volunteers
- Organising training of support volunteers
- Monitoring private Facebook group and LAMline to offer information and support
- Management of databases to record patient contact and preference information

Trustee support

- Organising and attending trustee meetings (approximately 3-4/year, mostly via Zoom), including minute taking
- Organising and attending annual meeting of members and women with LAM (in-person event, location varies)

Member engagement

- Attending to membership registrations and related matters
- Management and growth of member relationships
- Corresponding with members
- Maintenance of member database

Job description



Fundraising support

- Corresponding/follow-up with fundraisers
- Management of databases to record fundraisers and events
- Organising, assisting with and promoting fundraising events, e.g. London Marathon registrations and engagement with participants and PR consultants
- Conducting annual Christmas card campaign and/or similar campaigns

Donor engagement

- Corresponding/follow-up with donors
- Management and growth of donor relationships
- Management of databases to record donor contact and preference information

Bookkeeping support

- Downloading reports from Just Giving, Enthuse and similar sites
- Uploading income reports to [Xero]
- General bookkeeping duties] on [Xero]
- Maintaining a database system for Gift Aid claims
- Supporting the treasurer with Gift Aid claims
- Monitoring the charity bank account for donations

Office administration

- Creating and maintaining databases, including maintenance of data protection register
- Attending to petty cash matters
- Updating website and social media channels with charity events and news
- Assisting with production and distribution of thrice yearly newsletter
- Attending to insurance renewals and Charity Commission filings
- Attending to charity policies and agreements
- Liaising with other LAM patient organisations around the world
- Contact and interaction with the National LAM Centre and LifeArc Rare Respiratory Disease Centre

Job description



General skills

- Confident and compassionate
- Excellent interpersonal and communication skills
- Well organised and efficient
- Experienced in Microsoft Office programmes and other IT applications
- Self-starter and accustomed to working independently
- Knowledge of Gift Aid and Data Protection Act compliance
- Willingness and ability to work somewhat flexibly to accommodate occasional evening trustee meetings and urgent matters
- Bookkeeping
- Fundraising



How to apply



Your application should be submitted through the [Charisma website](#), and include:

- A comprehensive CV
- A supporting statement (no more than two pages) summarising why you're applying and how you meet the person specification

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

We welcome and encourage applications 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 for applications: 12th May 2026

Please note that applications will be reviewed as they are received, we therefore encourage early applications as we may progress candidates to interview before the application deadline.

Interviews with LAM Action will be held on a rolling basis.



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