



**METABOLIC  
SUPPORT**  
Living well with a  
rare disease

## **Job Description**

**Role: Fundraising Lead**

**Salary: £45,000 - £55,000 per annum F/T**

## **Background and Purpose**

Metabolic Support is the umbrella patient organisation for people living with and affected by Inherited Metabolic Disorders (IMDs). We are a UK-based organisation with an international reach. There are approximately 40,000 people in the UK living with one of around 2,000 IMDs. Globally an estimated 71,260 people are born with these conditions each year and 1.43 million people live with IMDs worldwide. IMDs are rare, lifelong genetic disorders that affect people in a variety of ways including lifestyle, lifespan, diet and medication needs and symptoms. Sadly, some disorders can cause irreversible complications or death.

Since our inception in 1981, we have been at the forefront of rare disease community development; as a founding member of EURORDIS, expanding newborn screening, accelerating the development of IMD treatments, and empowering our community through the Living Well Movement. We enable our inherited metabolic disorder community to live well by offering individual support, building connections, and developing evidence-based insight.

## **About the Role**

This is a strategic, hands-on opportunity to lead and shape our fundraising activity. You'll drive sustainable income growth and ensure our work is resourced to deliver real impact for people living with rare inherited metabolic conditions. This role will suit someone with ambition, emotional intelligence and a strong sense of purpose. We are a small team with a growing reach and are looking for someone emotionally intelligent, confident, great in a small team and who enjoys external partnership building.

As Fundraising Lead, you will:

- Lead the development of a cross-organisational fundraising strategy
- Build a high-performing fundraising function
- Position Metabolic Support as the leading international patient advocacy group for all those living with an inherited metabolic disorder
- Be an external ambassador for our community and their stories

You'll be the driving force behind an ambitious fundraising programme, shaping a bold strategy, unlocking new income streams, and building a diverse, future-proof pipeline. You'll lead on high-value bids and forge relationships with trusts, foundations, corporates and major donors, creating compelling propositions that inspire long-term support.

You will be a core member of the team, reporting to the Chief Executive and responsible for driving forward all aspects of fundraising. While this role currently has no direct reports, a key part of the position is working collaboratively across the whole team, embedding fundraising principles into every area of our work and maximising income opportunities across all team activities. We are a small but agile team and expect the successful candidate to be a self-starter with a "can do" attitude, lots of energy and an ability to work autonomously. This is an exciting opportunity to join a progressive charity and to work with a fun, committed and established team.

### **Main Responsibilities**

- Work with the Chief Executive to develop and implement a balanced and realistic fundraising strategy, which builds on our strengths and maximises income for the charity
- Deliver an integrated fundraising programme, which includes corporate partnerships, individual giving, major donors, trusts and foundations, legacies, community and events
- Develop diverse opportunities for individual giving and ensure outstanding donor stewardship
- Engage and strengthen relationships with supporters by working in partnership and drafting high quality presentations and pitches
- Ensure all fundraising activity is compliant with GDPR and relevant fundraising regulation and that all data is accurate and maintained efficiently
- Maintain and develop the donor CRM platform (Nutshell) including building supporter journeys to enhance donor experiences and maximise income for the charity
- Provide up to date funding reports and fundraising forecasts for the board
- With the CEO, manage all aspects of finance and reporting relating to fundraising, including annual budgets, monthly reporting and re-forecasting
- Work across the team to instil fundraising principles and identify and maximise income opportunities within all areas of the organisation's work
- Work with internal colleagues and external stakeholders to create impactful storytelling and supporter engagement opportunities to maximise revenue streams
- Work with the team to ensure that all opportunities to promote Metabolic Support and develop our fundraising and supporter engagement experiences are explored and maximised

*This job description is intended only as a guide to the range of duties involved. The post holder will need to be flexible and adaptable in order to respond to other duties that may be required from time to time and the changes and developments within the charity appropriate to the role.*

## **Required Experience & Skills**

- Proven experience working in a role with responsibility for income generation
- Experience developing and managing a diverse fundraising portfolio with significant expertise in at least one of: charitable trusts and grants, corporate partnerships, community fundraising or major donors
- Experience of managing fundraising budgets and ability to make informed forecasts about income and return on investment
- Experience of effective time management, working to tight deadlines and prioritising conflicting priorities successfully
- Experience in managing successful cross-functional relationships, internally and externally
- Excellent written and oral communication skills with the ability to organise and present information clearly and adapt communication to a variety of audiences
- Excellent organisational abilities with good attention to detail, including the ability to manage a high-volume workload and conflicting priorities
- Confident use of IT – including Teams, Microsoft Word, Excel, PowerPoint, Outlook, CRM databases
- A natural salesperson who can represent our charity and tell the stories of our community with confidence and clarity

## **Other Requirements**

- Excellent team player also able to work individually and remotely, with the ability to build and maintain positive, collaborative and trusting relationships
- Belief in and commitment to Metabolic Support's mission and values
- Willingness to work flexibly, travel within the UK and internationally (this role requires regular travel to conferences and events in the UK and abroad) and to undertake some evening/weekend work
- Eligibility to work in the UK and located in the UK