



METABOLIC SUPPORT ^{UK}

Your **rare** condition.
Our common fight.

Chief
Executive



Starfish

Introduction from the Chair

Dear Candidate,

Thank you for your interest in becoming our new Chief Executive. You will be joining the charity in its 40th year, with a vision to achieve advances across all care and services for people living with Inherited Metabolic Disorders (IMDs) and their families.

We exist for people living with the rarest forms of IMD's. We do this through individual patient support, building patient communities, empowerment and advocacy. Last year alone, we received almost 1,976 individual support enquiries from patients with 147 different IMDs. We built or regularly engaged with 44 patient communities living with IMDs, with a total of 38,289 members. With 30,574 unique users, we also saw a 30% increase on visits to our website – half of which were to our Covid-19 information hub.

While 2020 was a particularly challenging year for many, the pandemic also gave way to new ways of working and I am incredibly proud to be part of an organisation with such a dedicated team that has worked exceptionally hard and adjusted quickly to serve the on-going needs of our community. Last year, we adopted a new digital platform that brought us closer to IMD communities. While at times individuals can feel isolated, as a community we are now much closer together and able to give the much needed support to those that are living with one of over 500 IMDs in the UK.

We also published a new ten-year strategy that sets out our goals and ambitions as a charity to 2030. This strategy will put the patient voice at its heart, focusing on patient engagement and empowerment. By 2030, our goal is to grow our reach, with the agility and resource to support more people and provide better outcomes for those living with IMDs. Our strategy will ensure that MSUK remains not only current, but in the eye of the storm.

Our new Chief Executive will be essential in delivering against the strategy. You will build on the small existing team and unite people through a common vision. We are looking for a transformational leader who is collaborative, transparent and authentic, with a good understanding of small patient populations and their unique needs and challenges, and the drive to secure the future sustainability of the charity.

You may be operating as a CEO currently with a desire to lead an ambitious charity or you may be operating in a senior leadership role in a larger organisation looking to step into your first CEO role. Whatever your background, you will be passionate about the needs of people living with IMDs and will be committed to finding new, creative and impactful ways of working for us to provide the best possible support to those that need it most.

If you share our vision and want to be at the helm of a charity that has big ambitions for the coming years, then we would love to hear from you.

Dr Elin Haf Davies
Chair of Board of Trustees

About us

Metabolic Support UK (MSUK) is an umbrella patient advocacy organisation founded in 1981, supporting people living with Inherited Metabolic Disorders (IMDs) and their caregivers.

There are approximately 30,000 people in the UK today living with one of over 500 IMDs. These are rare, lifelong genetic disorders caused by an enzyme deficiency affecting the metabolic pathway which if undiagnosed or untreated, can cause irreversible complications, or sadly even death.

Focusing specifically on the rarest of the IMDs, those which have no other patient organisation or support group, MSUK delivers a wide range of support and advocacy services to address unmet needs. Using qualitative and quantitative data generated via various methodologies, our small, dedicated team works to proactively identify priority needs and develop evidence-based outputs and programmes to ensure the maximum impact for individual patients, collective patient communities and the wider IMD community.

We are a small team currently, with big ambitions. Our new Chief Executive will have the flexibility to build the rest of the team depending on skills requirements to deliver the strategy, e.g. in areas of advocacy, operations, fundraising and administrative support.



Our vision

By 2030, we want to see advances across all care and services for the IMD community; this includes early diagnosis, informed and empowered patients, and access to the treatments and services that are available to support families living with these conditions to enjoy a better quality of life.

The purpose of the role of Chief Executive is to lead on the vision and strategic plan to ensure that patients living with IMDs (and their caregivers) that are not represented by a disorder-specific patient advocacy organisation will:

- Receive compassionate and effective front-line support addressing their immediate practical and emotional needs.
- Be connected to others with the same condition to reduce isolation, via our 1:1 peer support programme or online disorder-specific communities.
- Be informed about their choices and empowered to assert their right to access care and treatments as well as the ability to apply good self-management.
- Have their voices heard and equally valued amongst all stakeholders and have the opportunity to participate in activities enabling MSUK to advocate for solutions to their unique challenges, including research, diagnosis, treatments, services and care.



Job Description

Role purpose

The Chief Executive will:

- Have overall responsibility and accountability for MSUK's aims and objectives, resourcing, organisation and operational planning and delivery of performance management.
- Drive the implementation of our ten year strategic plan and build a staff team to deliver the activity framework and ensure the effective measurement of impact.
- Deliver the ambitious income generation plan to ensure the future sustainability of the charity.
- Through a collaborative approach, become the key ambassador for MSUK with all external stakeholders, including the wider rare disease sector, and funding partners.
- Identify, develop and lead on a range of opportunities, as they occur, that contribute to the development of the charity, and the improvement of support and advocacy services to the IMD patient community.
- Work closely with the Board of Trustees to ensure good governance.

Key responsibilities

Strategic and Organisational Development

- Own and lead on the implementation of the ten year strategic plan, ensuring that impact is measured and reported against with key milestones and performance metrics.
- Ensure organisational targets and work plans reflect the agreed strategic objectives.
- Develop and maintain a productive relationship with the Chair and clear lines of accountability; support the Board to enable good governance.
- Review the skills requirements, and build, develop, and empower the staff team to deliver the strategy with optimal effectiveness.
- Create a positive working environment, culture and ethos suitable for a newly remote team, and lead by example.
- Ensure the effective performance management and development of all staff through regular team, 1:1 and review meetings.
- Implement and monitor employment policies and procedures.

Advocacy and External Profile

- Identify and generate productive strategic relationships with external stakeholders; work collaboratively with other patient organisations to ensure the best outcomes for patients.
- Be a key spokesperson and ambassador for the charity on the key issues faced by the IMD patient community, including diagnosis, access to specialised services and treatments and research.
- Maintain an awareness of the IMD and wider rare disease operating environment, and a good understanding of the unmet needs of patients.
- Develop and protect our position as the umbrella organisation for IMDs that do not have a disorder-specific patient organisation.
- Actively seek election to and effectively represent MSUK and the patient community as a stakeholder on relevant committees, and with regulatory bodies decision making processes.

Resources and Sustainability

- Oversee the effective management and monitoring of the charity's financial health, balancing internal and external demands.
- Lead on the charity's income generation plan, proactively seeking out new partnerships and identifying funding opportunities to ensure diverse income streams.
- Manage the relationships with existing partners, ensuring compliance with current commitments and maximise opportunities for enhanced collaboration and funding.
- Work with the Treasurer to prepare and manage the charity's annual budget.
- Regular reporting to the Board on income, expenditure and any budget variations.
- Ensure the charity remains transparent about its funding sources.

Person Specification

Knowledge and Experience

Essential

- A successful track record as a strategic leader within a charitable organisation, including working with a board, either as a Chief Executive or as part of a wider senior leadership team.
- Experience of successfully raising the external profile of an organisation by seeking out and developing strong collaborative partnerships with likeminded organisations and/or through the use of effective advocacy, lobbying and external affairs campaigns.
- Strong organisational change experience, with a background in developing infrastructure and resource for a growing organisation or directorate.
- Demonstrable track record of financial management and budgetary control, with the ability to set and monitor a budget within the scope of the organisation's priorities.
- Strong knowledge of fundraising, with a proven ability to successfully generate income via diverse streams.
- Good understanding of charity operations and governance.

Desirable

- Knowledge and understanding of the IMD or rare disease sector, or another sector with a small patient population.

Skills and Abilities

- Ability to earn and maintain the trust of those with whom the organisation deals, from patients and caregivers, to funders, collaborative partners, other stakeholder and key opinion leaders.
- Clear and visionary leadership skills, with the ability to inspire staff to reach their full potential and deliver against MSUK's strategic plan, identifying and developing new opportunities.
- An exceptional manager, with the ability to cascade objectives, plan and prioritise work effectively.
- A creative thinker with the ability to design new approaches to income generation and service delivery.
- Excellent presentation and external profile raising skills.

Style and Behaviour

- A bold, effective, brave and a proud external ambassador and lead spokesperson for the organisation.
- An inspiring leader who motivates high-performing teams to follow their example and supports people to grow in their careers.
- A strong role model who leads by example and embodies the appropriate behaviours of a senior leader.
- Inquisitive and challenging; constantly seeks improvement, both in themselves and in their team. Willing to test and learn from new approaches.
- A clear commitment to inclusion, diversity, and equality.

Terms of Appointment

Salary	The salary for this role is circa £65,000 per annum on a full-time permanent basis.
Location	This role can be based remotely, with some travel to Chester as required.
Pension	We offer a contributory pension scheme.
Annual leave	25 days annual leave (excluding public holidays), with one additional day per year of service (up to max. 30 days)
Working hours	We pride ourselves on facilitating flexible working where possible.



How to Apply

We hope you will consider making an application. If you have questions about the appointment and would find it helpful to have an informal conversation, please contact Katy.Giddens@starfishsearch.com or Mark.Crowley@starfishsearch.com and we will be happy to arrange a call.

To make an application, please go to <https://starfishsearch.com/jobs/metabolic-support-uk-ceo/> and click on the apply now button, with the following prepared:

- Your CV (no more than three sides)
- A supporting statement (no more than two sides) that sets out why you think this role is the right move for you and how you meet the knowledge and experience criteria.

Closing date:	Monday 15th March 2021
Preliminary interviews with Starfish:	w/c 22nd March 2021
Agreement of the final shortlist:	End w/c 29th March 2021
Interviews with Metabolic Support UK:	w/c 12th April 2021



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