



Dear Candidate,

Thank you for your interest in becoming the next Chief Executive Officer at the Association for Multiple Endocrine Neoplasia Disorders (AMEND). This is an exciting opportunity for a new CEO to lead our well-respected rare disease patient organisation through the next phase of change, growth and impact. You will find more information attached to this letter. If after reading this you change your mind, please let us know.

About Us

The Association for Multiple Endocrine Neoplasia Disorders (AMEND) is a UK-based charity registered in England and Wales (no. 1153890), dedicated to improving the lives of families affected by rare, often genetic cancers of the endocrine system. We provide vital free education resources and support services for affected individuals and families, raise awareness, drive research, and advocate for those living with these rare conditions. Learn more here: <https://www.amend.org.uk/>

About Rare Endocrine Syndromes and Cancers

The diseases that AMEND covers range from uncommon to extremely rare. Multiple endocrine neoplasia syndromes (MEN) predispose affected people to more than one tumour or cancer in different glands of the body. Hereditary paraganglioma syndromes (PPGL) predispose affected people to tumours of the adrenal glands and along the central and peripheral nervous system. Additionally, we provide services to the sporadic medullary thyroid cancer (MTC) and adrenocortical cancer (ACC) communities. Due to the genetic nature of many of the diseases within AMEND's remit, resources are usually available for all family members, from children to young adults and adults.

The Role

The new CEO will have a particular focus on improving financial sustainability and influencing health policy for these rare diseases. These sit alongside the other grass-roots duties of a small charity CEO, including working with our Medical Advisory Team to develop new and maintain existing patient education resources, and overseeing our support services including volunteers and a professional psychological counselling service. Reporting to and working with the Board of Trustees, the CEO will be responsible for delivering our 2027-2030 Strategic Plan, ensuring robust governance, and driving forward our mission to improve the lives of people affected by rare diseases. The CEO manages the part-time Executive Administrator and works with up to 30 current volunteers (patients, carers, and health professionals) to deliver services with impact. This role includes occasional weekend work, as well as approximately 15 days travel (national and international) per year to represent and advocate for the charities' beneficiaries.

Interviews

First round interviews will take place online in September. If you are invited for interview, we will contact you to ascertain your availability.

Yours

Gill Masters

Chair of the Board of Trustees of AMEND (outgoing)

AMEND CEO Application Pack

Job Description: Charity Chief Executive Officer

Charity: Association for Multiple Endocrine Neoplasia Disorders (AMEND)

Location: negotiable (Tonbridge, Kent office / hybrid working / homeworking) UK only

Salary: up to £55,000 p.a. depending on experience

Hours: 40 hours per week (+ occasional weekend work, evening meetings, and up to 15 days national/international travel per year)

Term: permanent

Notice period: Notice period of 3 months. This post is subject to a 6-month probationary period.

Key Responsibilities

- Provide dynamic leadership, setting the strategic direction in partnership with the Board.
- Act as the primary ambassador for the charity, representing the organisation to stakeholders including patients, families, clinicians, researchers, national and international medical societies, umbrella advocacy organisations, policymakers, and funders.
- Drive sustainable income generation, diversifying funding streams through fundraising, partnerships, and grant opportunities.
- Support the creation of high-quality services, advocacy, and support for our rare disease community, including:
 - Educational and support events for beneficiaries
 - Patient Information production and review
 - Monthly e-newsletters
- Working with the Board to ensure compliance with charity law and regulatory requirements, maintaining best practice in governance and financial management.
- Build, lead, and motivate a high-performing team and culture, whether staff or volunteers.
- Champion innovation in research collaboration, policy engagement, and awareness-raising.

About You

We are looking for an exceptional leader who brings:

- Proven senior leadership experience within the charity, healthcare, research, or related sectors.
- An excellent track record of income generation, fundraising, or partnership development.
- Strong strategic and financial management skills, with the ability to balance vision with operational delivery.

AMEND CEO Application Pack

- Outstanding communication and advocacy skills, with the confidence to engage effectively at all levels, including clinicians, government, and the media.
- A collaborative, empathetic, and resilient approach, with the ability to inspire and motivate others.
- Passion and commitment to making a difference for people affected by rare cancers and genetic diseases.

Qualifications Preferred

- University degree level education
- UK non-profit leadership role of 3+ years
- Evidence of continued professional development

Why Join Us?

This is an exciting and unique opportunity to lead a small but dynamic charity that is well-known and respected by its beneficiaries as well as within relevant medical circles. You will play a pivotal role in running the day-to-day charity activities, as well as growing the charity, shaping services, influencing policy, and championing the voice of communities that too often go unheard.

Benefits

Pension

Flexible working pattern

30 days annual leave

Equal Opportunities Employer

We are an equal opportunities employer. We value diversity and do not discriminate on the basis of age, disability, gender, race, religion or belief, sexual orientation, or any other protected characteristic.