

EDIN Operations & Strategy Director

Position: Operations & Strategy Director (professional consultant)

The Ectodermal Dysplasia International Network (EDIN) seeks to fill the role of Operations & Strategy Director. The purpose is to stabilise and consolidate EDIN as a global hub for information and support for ED communities across patient associations, medical research, clinicians and industry.

The role will be based on remote work, reporting to the EDIN Vice Chair and wider EDIN Executive Committee (Ex-Com).

The role is part time and requires a broad range of competencies, with the ideal candidate having demonstrated experience with fundraising, grant writing, strategy & policy planning and, coordination & liaison globally across different fields such as academia, clinical research and patient associations. Weekly working hours may vary, we estimate in the range of 10-15 hours per week.

Further information is included in this document and applications (via email) are open until 2pm (CET) Monday, 31 August 2026.

Role Overview:

Position	Operations & Strategy Director (professional consultant)
Rate	Hourly rate negotiated with successful candidate based on skills and experience
Work Location	Remote Flexible Worldwide
Hours	<ul style="list-style-type: none"> • 10 to 15 hours per week maximum • EDIN Executive Committee is based worldwide and generally meets at 2pm CET every 6-8 weeks • Hours may be during non-traditional office hours to be able to connect with EDIN Ex-Com members & ED Leaders worldwide in their time zones
Start Date	1 November 2026
Length of Service Contract	1 Year with a trial period of 4 months, contract potentially renewable

Responsibilities:

Cooperating with our Administration Officer and reporting to EDIN's Vice Chair. The Operations & Strategy Director will deliver exceptional strategic planning, coordination, liaison, fundraising and stabilisation of EDIN. Responsibilities include:

Fundraising

- Conference sponsorship
- Grant & philanthropic application writing
- Corporate relationship development
- European government funding opportunities

Strategy & Policy

- Develop EDIN 1/5/10 year Strategic Plan & Road Map with Ex-Com
- Drive policy change & international advocacy/lobbying
- Increase research opportunities & publications
- Build infrastructure to reduce reliance on volunteer Executive Committee

Coordination

- Central hub connecting researchers, clinicians, and patient associations
- Biannual conferences & leaders' meetings (scientific, industrial, fundraising)
- Project management across subject areas and geographies
- Industry representation & engagement

Global Support

- Knowledge sharing, best practices & social media across patient associations
- Resources for newly established organisations worldwide

Stakeholder Liaison

- Medical, scientific & research communities
- Industry, pharma & clinical trials
- Peak bodies & global partners

Reporting

- Take directions from and liaise with Ex-Com Vice Chair, report to EDIN Ex-Com on all projects, KPIs, deliverables and strategic plan progress

Key Selection Criteria

- Proven self-leadership, drive, initiative and integrity. Good ability to carry out a mandate independently and work effectively in a remote, autonomous environment
- Demonstrated results in fundraising, strategic networking, policy/advocacy and coordination
- Stakeholder engagement experience across a diverse range of (rare disease) communities, clinicians, researchers, government, and industry
- Project management skills: Organised, detail-focused, juggle priorities and meet deadlines
- Fluency in English (additional world language an advantage) and proficiency in Microsoft Office and AI/digital tools
- Able to provide structured reporting to EDIN's Executive Committee, seek guidance appropriately, and operate with transparency and accountability

Desirable Selection Criteria

- Experience in a comparable national or international role
- Familiarity with rare disease/disability sectors, sensitivity to lived experience of those affected
- Ability to work professionally in French

Other Relevant Information:

- The appointee will be subject to a mutual contract termination clause of 1 month.
- The position will be subject to a National Police Records Check and Working with Children/Working with Vulnerable People Check, as applicable in the successful candidate's country.
- As this is a consultant role, the appointee will be responsible for
 - Ensuring all appropriate insurances are held (PI, PL, Cyber)
 - Pay own taxes in their work location / country
 - Provide own equipment (phone / computer), office space
 - Maintain secure and reliable internet service.
- EDIN is an equal opportunity organisation and welcomes applicants from a diverse range of backgrounds.



About the Organisation:

The Ectodermal Dysplasia International Network (EDIN) is a hub for the international Ectodermal Dysplasia patient association leaders to share information, support and encourage medical and clinical research and to encourage best practice sharing for patients and relatives within individual countries.

EDIN was established in 2007 and is an umbrella organisation facilitating greater collaboration between Ectodermal Dysplasia leaders around the world working together to develop and share information linked to all aspects of life with ectodermal dysplasia.

“Our vision; a world in which no one faces their rare disease journey alone.”

Together, we provide a strong world voice. By working in partnerships with patient associations and professionals, we are breaking the isolation felt by those living with Ectodermal Dysplasia, striving to drive policy issues and propel medical research.

The EDIN is run by a volunteer Executive Committee (Ex-Com) made up of the following members:

1. Chair, Mette Anthonsen, Svenska Ed-föreningen, Sweden
2. Secretary General & Vice Treasurer, Thomas Counioux, AFED - Association Francaise Dysplasies Ectodermiques, France
3. Treasurer, Diana Perry, ED Society, UK
4. Vice Chair, Ulrike Holzer, Selbsthilfegruppe Ektodermale Dysplasie e.V., Germany / Austria / Switzerland
5. Vice Secretary General, Greg Klimovitz, NFED - National Foundation for Ectodermal Dysplasias, USA
6. Administration Officer & Ex-Com Member, Beth Ferlazzo, ozED - Australian Ectodermal Dysplasia Support Group, Australia
7. Ex-Com Member, Lars Utzon, ED Danmark Ectodermal Dysplasia, Denmark
8. Ex-Com Member, Manuel Chicano, AADE - Asociación de Afectados por Displasia Ectodérmica, Spain

Apply for This Position:

Applications for this consultant role will be accepted until 2pm (CET) Monday, 31 August 2026 via email with subject line “*Application for Operations & Strategy Director Role*” to Beth Ferlazzo beth@edinetnetwork.org EDIN’s Administration Officer.

All Applications must include:

1. Letter addressing the **Key Selection Criteria**
2. Professional Profile
3. Proposed Fee / Rate
4. Relevant business / consultant insurance certificates
5. References / Testimonials
 - a. Note: References will be required to be supplied by shortlisted candidates

Queries:

Please contact EDIN Chair Mette Anthonsen, mette@edinetnetwork.org or Vice Chair Ulrike Holzer, ulrike@edinetnetwork.org via email with any questions you may have about this role.