NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

Director of Research

About the NFED

Together, we enrich the lives of people affected by ectodermal dysplasias by fostering community, providing education and support, and driving advocacy and groundbreaking research—creating a brighter future for all.

The Opportunity

Reports To: Executive Director
Location: Remote/Hybrid
Travel: 10-15% (conferences, research meetings—opportunities to build national connections)
Compensation: $75-85k plus health benefit stipend, FSA, employee matching IRA, and paid vacation

Imagine being the bridge between scientific discoveries and families seeking hope. As the Director of Research, you will facilitate collaborations that transform research into real answers, working alongside world-class field experts and resilient individuals and families to shape the future of rare disease research.

What You'll Do in Your First Year

- **Connect** with NFED's Scientific Advisory Council, distinguished experts who will become valued collaborators
- **Manage** the Ectodermal Dysplasias Patient Registry in partnership with the IAMRARE program through the National Organization for Rare Diseases (NORD)
- **Collaborate** with international partners and PIs in an innovative Edelife clinical trial
- **Facilitate** research conferences and grant distributions where science meets hope
- **Build relationships** with research partners and other peer organizations to explore new possibilities
- **Tell stories** that translate science into accessible communications to inspire families and engage current and prospective stakeholders
- **Advocate** for NIH research funding for rare disorders and other NFED priorities

Key Responsibilities

Research Leadership & Facilitation
- Coordinate research projects and facilitate collaborations between scientists and NFED patient community
- Serve as primary liaison to Scientific Advisory Council
- Translate research findings into clear, hope-filled communications
- Track projects, funding, and progress; ensure all research projects are IRB approved
- Complete CITIs online training and maintain certification
- Collaborate with Registry principal investigators to develop natural history studies based on registry date

Strategic Partnerships
- Cultivate relationships with researchers, academic institutions, and corporate partners
- Bridge the scientific community and patient families with empathy and mutual respect
- Identify funding opportunities in collaboration with development staff

Conference Planning & Thought Leadership

- Develop agendas for research conferences, symposia, and medical grand rounds
- Represent NFED at national and international conferences
- Promote best practices across patient advocacy networks

Program Management & Communication

- Manage grant program logistics—proposals, review processes, tracking
- Partner with the communications team on research updates and educational resources
- Support production of reports and research reviews

What You Bring

Required:

- Minimum of three to five years of work experience in related field, e.g. patient advocacy, healthcare research, or rare disease organizations
- Advanced degree (Master's or Doctorate in Public Health, Health Policy, Life Sciences, Social Sciences, or related field)
- Knowledge of research methodologies or patient-centered research design
- Exceptional communication skills—ability to engage authentically with scientists, clinicians, families, and funders
- Strong organizational and project management abilities
- Collaborative leadership style
- Genuine empathy and the ability to support families during vulnerable moments
- Willingness to learn and bring fresh ideas to patient advocacy

Strongly Preferred:

- Conference planning background
- Grant writing experience
- Genetic knowledge and experience working in a genetic field

What We Offer

Impact: Make a tangible difference for families navigating rare conditions. Your work directly shapes their access to hope and breakthroughs.
Growth: Build national visibility while advancing your expertise in patient-centered research.
Collaboration: Work with passionate colleagues, world-class researchers, and the inspiring Scientific Advisory Council.
Innovation: Shape the NFED's next era with fresh ideas for funding, advocacy, and positioning.
Benefits: Competitive salary, benefit stipend, FSA, employee-matching IRA, generous PTO, professional development support, remote/hybrid flexibility.

To Apply

Submit your Resume/CV, Cover Letter and Three References online: www.nfed.org/DoR26
Deadline: April 6, 2026

Our Commitment

NFED is an equal opportunity employer committed to diversity and inclusion. We especially encourage applications from individuals with lived experience of rare diseases.

Questions? Contact Greg Klimovitz, Executive Director greg@nfed.org