



Title: Director of Communications

Location: Remote

Job Type: Full-time, exempt

Reports To: Executive Director

Oversees: Two part-time marketing and communications contractors

Salary: \$80,000, plus health benefit stipend, FSA, employee matching IRA, and paid vacation

The Role

The Director of Communications is a member of the NFED's senior leadership team and creative thought partner to the Executive Director. This role is ideal for a communications professional who can bring fresh ideas, strong storytelling instincts, and a passion for serving a global rare disease community.

The Director leads all NFED communications, marketing, digital content, and brand management, with a major emphasis on creative educational content and leading the refresh of NFED.org. This is a hands-on leadership role: the Director both sets direction and actively creates, schedules, and publishes content, while managing two part-time marketing and communications contractors and working across the team to share the NFED's story with clarity and heart.

Key Responsibilities

Strategy and Brand

- Design, implement, and evaluate the NFED's annual communications plan in partnership with the executive director and the NFED staff.
- Serve as steward of the NFED's brand voice and visual identity across all channels and materials.
- Use data and analytics to measure engagement and improve results.

Creative and Educational Content

- Lead creation of engaging educational content for TikTok, YouTube, Instagram, LinkedIn, Facebook, website, and other platforms, making complex medical and research information accessible for a general audience. Own the content calendar and write, schedule, and publish social media posts, e-newsletters, and email campaigns, coordinating timelines across departments.
- Elevate the stories of individuals and families affected by ectodermal dysplasias in ways that are respectful, authentic, and inclusive.
- Foster a welcoming, responsive online community.

Website Leadership

- Lead the NFED.org website refresh, coordinating staff input, vendor selection, and implementation.
- Champion a modern, responsive, and accessible site design, and maintain standards and regular updates after launch.

Collaboration and Project Leadership

- Partner with the Executive Director and Development Coordinator to provide creative messaging and design for appeals, stewardship, sponsorships, and impact reports.
- Manage contractor priorities and deliverables, and oversee projects using Asana and Google Workspace.
- Identify responsible, practical ways to use AI tools to enhance creativity and efficiency.

Qualifications

- Four or more years of experience in communications, marketing, or digital content, with a portfolio demonstrating creative work.
- Bachelor's degree in a related field, or equivalent experience.
- Experience managing contractors, vendors, or staff.
- Excellent writing, editing, and storytelling skills, especially in communicating medical or scientific information to general audiences.
- Hands-on experience with social media scheduling and email marketing.
- Ability to manage a budget relevant to communications projects.
- Demonstrated experience creating short-form video and social media content.
- Familiarity with AI tools (such as Claude, ChatGPT, or Gemini) and curiosity about using them responsibly.
- Proficiency with Microsoft 365, Google Workspace, Asana, Canva, and WordPress desirable.
- Experience with website redesign, SEO, GEO, or accessibility standards.
- Creative, organized, collaborative, and ability to thrive in a remote workplace.
- Genuine affinity for the NFED's mission and heart for serving our community.
- Ability to travel occasionally, primarily for the annual NFED Family Conference and annual staff meetings.

Why Join the NFED

This role offers a seat on a senior leadership team with a direct voice in shaping the NFED's future, high-visibility projects including a full website refresh and a growing educational content library, professional development support, and connections with leaders across the rare disease community through our national and international partnerships.

To Apply

Submit your Resume/CV, Cover Letter and Three References online:

www.nfed.org/DirComm

Deadline: November 2, 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