

Director of Development

National Urea Cycle Disorders Foundation

Position Details

Part-time (32 hrs/week) with path to full-time | Remote | \$80,000–\$90,000 | Reports to Executive Director

NUCDF is looking for a fundraiser who wants to build — someone who gets energy from designing campaigns, creating systems, and cultivating relationships. As our first-ever Director of Development, you will shape the philanthropic future of a highly respected national nonprofit at a thrilling moment in rare disease research.

We welcome candidates who may be new to the world of rare diseases and urea cycle disorders. We are looking for a creative, driven development professional who loves the craft of fundraising and wants the kind of ownership that is hard to find at a larger organization, and wants to be close to the community they serve.

This is a unique opportunity to step into a builder role at a national nonprofit that is:

- Advancing life-changing research
- Supporting families who are passionate about community-building
- Connecting with researchers, clinicians, pharmaceutical companies, and families on a regular basis
- Driving momentum toward better treatments—and ultimately, a cure

If you've been waiting for a role where you can design new strategies, craft original storytelling, and make a large impact, this is it.

About NUCDF

The National Urea Cycle Disorders Foundation is the only nonprofit in the country solely dedicated to improving and saving the lives of people affected by urea cycle disorders (UCDs), which are rare metabolic conditions that, without proper management, can be life-threatening. NUCDF funds research, supports families, drives advocacy, and works alongside leading clinicians, researchers, and industry partners to accelerate better treatments.

The science is moving fast. Gene therapy, RNA technologies, and new FDA-approved treatments are reshaping what is possible for UCD patients. NUCDF has been at the center of that momentum, including through high-profile advocacy work like the ongoing collaboration with the NIH-supported Rare Diseases Clinical Research Network and the widely followed Baby KJ story that arose from the UCDC natural history study data. The community is engaged, the mission is urgent, and the opportunity to build something lasting is real.

The Opportunity

NUCDF has been investing in its development infrastructure by working with a fundraising agency, building a strong Board of Directors, and establishing an organizational brand with decades of credibility behind it. Now we are ready for our first in-house development leader to take the wheel.

This fully remote role begins at four days per week with flexible hours, with a genuine goal of growing into full-time as revenue expands. We are open to keeping it part-time long-term if that is what works best for the right candidate.

You will have the support of an influential Executive Director, an engaged Board of Directors, and a collaborative staff. Together, we will build upon our strong momentum to expand our development program, serve more families, and fund more groundbreaking research.

What You Will Do

Lead Fundraising Strategy

- Develop and manage NUCDF's annual Development Plan in partnership with the Executive Director, including revenue targets, fundraising strategies, and campaign timelines.
- Create a donor communications strategy so that our messaging, storytelling, and social media strengthen donor engagement and visibility.
- Serve as Chair of the Board of Directors Development Committee, helping guide board engagement in fundraising

Manage Annual Campaigns

- Design and implement at least two annual fundraising campaigns a year incorporating print, digital, and sometimes peer-to-peer (P2P) components. P2P experience is valued, but not required.
- Lead fundraising and strategic partnerships for NUCDF's annual flagship events: Cure the Cycle and the Family Conference through corporate sponsorships, family fundraisers, and P2P team captains.
- Design and implement annual awareness campaigns: UCD Awareness Month (April) and CheckAmmonia (October) in partnership with the Social Media Manager with an eye towards engaging NUCDF's donors in awareness activities online.
- Lead the Cindy Le Mons Legacy Giving Society program marketing, solicitation, and stewardship with the Executive Director.

Grow Individual Giving

- Oversee and optimize mid-level giving and annual fund programs, bringing fresh new ideas to engage and retain donors.
- Design and facilitate NUCDF's formalized major donor program in partnership with the Executive Director and create individualized major donor solicitation and stewardship plans.
- Manage and optimize the organization's donor database (Network for Good) to ensure accurate tracking, segmentation, and reporting.
- Oversee donor stewardship processes, including timely and meaningful acknowledgement of gifts to ensure every donor feels valued.

Write and Manage Grants

- Identify foundation and corporate prospects.
- Write grant proposals and reports.
- Manage the pipeline of foundation and corporate grant submissions and conduct relationship management in partnership with the Executive Director.

Who We Are Looking For

We are most excited about candidates who are strong fundraising generalists with at least three years of progressive nonprofit development experience. Whether you are a high-performing Development Manager ready to step into your first director role, or a seasoned Director looking for a four-day-week remote position with real creative ownership, we want to hear from you.

Qualifications:

- 3+ years of progressive nonprofit development experience
- Bachelor's degree in a related field; advanced degree or certifications in nonprofit management or fundraising preferred.
- Demonstrated success managing fundraising campaigns or development projects
- Proficiency in fundraising strategies and implementing impactful donor engagement programs.
- Experience with annual fund or mid-level giving programs
- Strong writing skills, including grant writing and/or donor appeals
- Experience with Canva or similar design tools
- Proficiency in a CRM or donor database (Network for Good or similar)
- Excellent organizational skills and comfort managing multiple projects independently
- A genuine love of both written and visual storytelling
- Passion for mission-driven work and empathy for families navigating serious health challenges

Bonus experience (valued but not required):

- Peer-to-peer fundraising
- Major gift fundraising
- Grant writing experience
- Health nonprofit, rare disease, or patient advocacy sector

Compensation & Schedule

- **Salary:** \$80,000–\$90,000 for 32 hours per week
- **Schedule:** Fully remote, flexible hours, Eastern time zone preferred but not required.
- **Growth path:** This role is expected to grow into full-time as development revenue expands; we are also open to keeping it part-time if the right candidate prefers.
- **Travel:** Occasional travel 1-2 times a year for fundraising events and our annual conference.
- **Professional Development:** Training and coaching to grow fundraising skills.
- **Benefits: Retirement Plan:** Employees are eligible to participate in NUCDF's retirement plan, which includes a 3% employer match on eligible contributions, following 6 months of employment. While this position does not currently include employer-sponsored health insurance, we are committed to evolving our benefits offerings as the organization grows.

Why NUCDF

The rare disease space is one of the most collaborative and mission-driven corners of the nonprofit world. The families, clinicians, and researchers in the UCD community are remarkable people who you will get to know well. NUCDF sits at the intersection of multiple thrilling advances in research, healthcare advocacy, and family support.

You do not need to arrive knowing about genetic research, UCDs, rare diseases, or drug development, but we hope you feel as inspired as we do to champion treatments and cures.

This is an opportunity to build a development program from a strong foundation, at a moment when the science and the community momentum are genuinely exciting. You will be creating strategies, building programs, and seeing your work translate directly into outcomes for families. If you are the kind of fundraiser who wants ownership, creativity, and purpose — this role was designed for you.

How to Apply

Please send a resume, cover letter, and one writing sample (a grant proposal, grant report, or donor appeal is ideal) to:

CureUCD@nucdf.org

Applications will be accepted through April 17th. We review applications on a rolling basis and encourage early submissions.

NUCDF is an equal opportunity employer committed to building a team that reflects the diversity of the communities we serve and to fostering a workplace where all individuals feel valued, respected, and included. We are dedicated to creating a diverse, inclusive, and equitable environment and do not discriminate on the basis of race, color, religion, sex, sexual orientation, gender identity or expression, national origin, age, disability, veteran status, genetic information, or any other protected characteristic under applicable law.