



Executive Director

About NOAH:

The National Organization for Albinism and Hypopigmentation (NOAH) was founded in 1982, NOAH serves the albinism community by creating a space that fosters acceptance, support and fellowship.

NOAH is a not-for-profit corporation chartered in Pennsylvania and has a 501(c)3 tax-exempt status. NOAH is a registered charity in all U.S. states requiring such registration. Additional state nonprofit disclosure information is available at www.albinism.org/state-disclosures.

Vision

We envision a world where people with albinism are empowered to be fully-functioning members of society, where barriers and the stigma of difference no longer exist, and where people with albinism have a quality of life that is rewarding, dignified and fulfilling.

Mission

NOAH's mission is to act as a conduit for accurate and authoritative information about all aspects of living with albinism and to provide a place where people with albinism and their families in the U.S. and Canada can find acceptance, support and fellowship.

Governance

NOAH is governed by a board of directors. The [NOAH Board of Directors](#) is made up of 13 to 18 people. Up to 12 directors are appointed by the board and serve four-year terms. The term year begins June 1st. One director is a permanent representative of the Hermansky-Pudlak Syndrome Network.

Duties and Responsibilities:

The Executive Director shall lead NOAH in the overall daily operations of the organization including but not limited to; strategic development, resource development, public relations, communications, marketing, program development and implementation, as well as other areas deemed pertinent to the growth and development of the organization. This is a remote position, allowing the individual to work from anywhere in the U.S. Travel would be required to attend conferences, board meetings and other important events.

Duties will include the following:

- Collaborate with the NOAH Board of Directors in advancing NOAH's mission and vision
- Manage, supervise and direct the day-to-day operations of the organization
- Ensure the fiscal wellbeing of the organization, by taking a leadership role in fundraising efforts, developing new and innovative revenue streams, writing grants, managing donor relations and diversifying philanthropic initiatives.
- Develop and manage the annual operating budget
- Lead albinism awareness efforts and community outreach, which may include attendance at professional conferences, making presentations, and meeting with stakeholders
- Support all NOAH programs including the biennial National Conference, social events (both virtual and in-person), educational initiatives and support services for newly-diagnosed families
- Manage a team of volunteers, employees and/or independent contractors retained by NOAH who are dispersed throughout North America
- Attend and contribute to monthly board calls and semi-annual in person board meetings by offering succinct and meaningful updates

about the organization's achievements, operations, development and communications, financial wellbeing and progress toward achieving strategic plan goals.

- Build NOAH's community and volunteer infrastructure
- Collaborate with NOAH consultants on projects related to areas such as strategic planning, information technology and event planning

The Executive Director duties may be modified and supplemented by the Executive Committee of the board of directors at any time.

Qualifications / Skills:

While no one candidate will possess every quality outlined for this position, our ideal candidate will fit many of the following competencies and personal attributes:

- Knowledge of issues affecting the albinism community
- Sensitivity to the unique needs and concerns of rare conditions such as genetic disorders, disability or low vision/blindness
- Experience and skill in working collaboratively with a board of directors
- Extensive fundraising experience and the ability to lead new, engaging and recurring fundraising efforts
- Prior experience developing, managing and evaluating programs
- Strong business acumen with skill in overseeing budgets and strategic plans
- A track record of effective leadership including the demonstrated ability to recruit, organize, inspire and manage a diverse team of staff and volunteers
- Solid organizational abilities including project management, planning, delegating, program development and task facilitation
- Strong interpersonal and community-building skills evidenced by past experience initiating and growing meaningful collaborations with diverse groups of stakeholders to include medical professionals, researchers, the media, government organizations, families, educators, major donors and disability advocacy organizations

- Strong written and oral communication skills with notable comfort and skill making presentations to large groups and diverse audiences
- Demonstrated commitment to fostering a diverse, inclusive and welcoming community
- A high degree of accountability, integrity and stewardship

Education and Experience Requirements:

- Bachelor's degree
- At least four years of 501(c)3 non-profit management experience sufficient to demonstrate potential success in this leadership position
- Prior management or supervisory experience

Completion of a criminal and financial background check will be a condition of employment. Candidates must be eligible to work in the United States.

If you believe you can play a part in the future of NOAH, we'd love to hear from you. Please submit your resume or CV along with a single-page personal statement explaining your interest in this position to edapplication@albinism.org. NOAH's goal is to be a diverse organization that is representative of the community that we serve. As such, we welcome applications from candidates from diverse backgrounds, including individuals with disabilities.