



Research Program Committee POSITION DESCRIPTION

PRIMARY CONTACT: NOAH's Executive Director

EFFECTIVE DATE: 6/29/2023

RESEARCH PROGRAM SUMMARY:

NOAH will become a leading voice in albinism research through the work of its Research Program. NOAH encourages all legitimate and ethical scientific and medical research that will improve the understanding, diagnosis and management of all forms of albinism.

RESEARCH COMMITTEE STRUCTURE:

Committee members shall consist of a diverse group of community members committed to advancing albinism research. The Executive Director is a permanent member of the committee. At least one NOAH Board member will sit on the committee.

Committee members will be asked to serve a minimum 2-year term with continued service. New committee members are selected by the current committee and approved by the Executive Director. Multiple terms are permitted.

The number of committee members is directed by the activity and nomination of representatives from across NOAH's diverse community.

KEY RESPONSIBILITIES:

As a NOAH Research Program Committee member, you will be asked to do the following:

- Support the mission and vision of NOAH
- Attend scheduled meetings and participate in group discussions.
- Assist in the overall management of the grant process to ensure that funded research will be patient-centered and will help develop a greater understanding of albinism.
- Actively participate in a scientific peer-review process to identify methodologically rigorous research proposals and award grant funding.
- Consult with the Executive Director on research-oriented external facing content and make appropriate recommendations in formalizing program offerings.

- Support community engagement and fundraising efforts of the organization.
- Uphold a commitment to diversity, equity and inclusion
- Provide timely response to written communication from NOAH staff, fellow committee members, and the NOAH community
- Keep informed about plans, activities and needs of the organization.

EXPECTATIONS:

TIME COMMITMENT:

- Committee members will be asked to serve a **minimum 2-year term**.
- Approximately **4 hours per month** shall be dedicated to committee service.
 - Any scheduled NOAH Research Program Committee meeting (typically via Zoom)
 - Email exchange
 - Review grant letters of intent / applications with NOAH Scientific Advisory Board and determine awardees based on discussion with fellow committee members. (Annually, or as funds are available.)
- Attendance at NOAH's biennial conference is encouraged

DESIRED ATTRIBUTES:

- Person with albinism (PWA) or family member of PWA.
- Previous association with NOAH / participated in a NOAH event
- Ability to work well with a group and engage in open and respectful discussion
- Previous experience in any of the following areas - scientific research, medical field, vision-related services, dermatology, fundraising / development.