



Patient and Family Advisory Board Policy and Member Agreement

Adopted November, 2022

The mission of ANA is to represent, serve, and support the North American community of persons affected by aniridia and their families, patient advocacy organizations, and clinicians and scientists. ANA aims to facilitate direct interaction and meaningful engagement with persons affected by aniridia and their families throughout North America. The first step in giving patients and families a voice in ANA is the creation of a Patient and Family Advisory Board.

It is essential that ANA ensure that its strategic plan supports persons affected by aniridia and their families. The best way to discover and understand what patients and their families truly need/want is to receive their input. The Patient and Family Advisory Board (PFAB) will take a cross section of the North American community of persons with aniridia and their families and give them opportunities to provide input into the ways that ANA carries out its mission.

Purpose

The purpose of the Aniridia North America (ANA) Patient and Family Advisory Board (PFAB) is to

Provide persons with aniridia and their family members a pathway to actively engage with ANA, identify opportunities for patient community engagement, and provide feedback from a patient perspective regarding the plans, activities, and patient-oriented materials and programs of ANA

Structure

Leadership: The Chair of the PFAB will be a member of and elected by the current ANA Board of Directors.

Composition: The PFAB will consist of 6-16 members, who have been invited to serve by the ANA Board of Directors (BOD). PFAB members serve at the discretion of the ANA Board of Directors.

The composition of the PFAB will be drawn from the ANA Board of Directors and the following groups that make up the North American aniridia community:

- Persons with aniridia (“patients”)
- Family members of persons with aniridia
- Official representatives from partner and stakeholder organizations

Every effort will be made to choose individuals who represent a cross section of the regions, countries, languages, and ages that make up the North American aniridia community. Diversity and inclusion are important values of ANA and every effort will be made to have membership equally represented. As much as possible, membership shall equally represent the three groups listed above. Some members may represent more than one of the groups listed above.

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Eligibility: Members of the PFAB must be willing to support and assist with the mission, goals, objectives, vision, and values of Aniridia North America. Individuals should be active in the aniridia community and possess excellent communication skills.

Terms: PFAB members will serve for terms of two (2) years. At the end of a term, a PFAB member may be invited to serve for another term, with no limit to the number of consecutive terms permitted, though rotation of membership is expected. A member of the PFAB may resign by submitting a written notice to the Aniridia North America Board of Directors. At any regular meeting or special meeting called for this purpose, the Aniridia North America Board of Directors may elect/invite a new member or fill a vacancy on the PFAB.

Compensation: Members of the PFAB are volunteers and will receive no compensation for their time or their expertise.

Benefits: Members of the PFAB may be invited to attend ANA-sponsored events at their own expense, even if the events are not otherwise open to the patient community.

Meetings/Frequency

Meetings should occur at least biannually via Zoom. In addition to the PFAB committee meetings, individual members may be called upon outside of meetings to provide feedback on activities and assist with projects as needed.

Roles and Responsibilities

Members of the Patient and Family Advisory Board are expected to be active participants in and advocates for Aniridia North America. Members may be asked to assist ANA in a variety of ways, depending on their interests and abilities as well as the needs of the organization. Duties will be distributed amongst PFAB members and may include, but are not limited to:

- Attending meetings on a regular basis, contributing knowledge and experience to discussions, and being respectful of other members' opinions, time, and confidentiality
- Making recommendations to the ANA Board of Directors concerning programs and activities that would be advantageous to the North America aniridia community
- Reviewing materials to be distributed to the patient community and providing constructive critique for their improvement
- Ensuring that other members of the PFAB and the ANA BOD are kept abreast of important topics of discussion in the North America aniridia community
- Providing guidance and support to Aniridia North America in the creation and execution of targeted awareness programs directed toward various segments of the North American aniridia patient community
- Assisting with the dissemination of information and communication among all aniridia-related stakeholders in North America

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- Allowing his/her name and/or likeness to be displayed as a member of Aniridia North America's Patient and Family Advisory Board on various ANA publications and/or on the ANA website: <https://www.aniridia.org>

Confidentiality

In carrying out the above listed duties, each member of the PFAB will be responsible for keeping certain information about ANA, researchers, ongoing research, grants, and individual patients confidential, as dictated by regulation (e.g., HIPAA), high medical ethics standards, or as requested by ANA.

Conflict of Interest

As representatives of the ANA, members of the PFAB have an obligation to avoid actual or potential conflicts of interest. An actual or potential conflict of interest occurs when a member of the PFAB is in a position to influence a decision that may result in personal gain, gain for a friend or relative, or benefit for another organization as a result of ANA's activities. Conflicts of interest prevent members from exercising their best judgment, and even the appearance of a conflict of interest may damage the reputation of ANA. Members of the PFAB are required to disclose any actual or potential conflicts of interest to the Board of ANA, so that safeguards can be established to protect all parties.

I have read and agree to abide by the Mission, Vision, and Values of ANA and the above Policy:

Name _____

Date _____