

## 1. Purpose

The PFIC Network's Board of Directors governs the organization's strategic and organizational management and are committed to furthering the PFIC Network's mission to improve the lives of patients and families worldwide affected by Progressive Familial Intrahepatic Cholestasis, PFIC.

## 2. Structure

**Composition:** Board of Directors will include individuals with a diverse range of professional and personal backgrounds to support the needs of the organization. The Board of Directors will consist of three to 11 members, who have been invited to serve by the active Board of Directors of the PFIC Network.

**Eligibility:** Members of the Board of Directors must be passionate about the PFIC Network's mission, goals, objectives and values. Selected Board of Directors will have achieved leadership stature in business, community involvement, healthcare, philanthropy, or the nonprofit sector and are willing to support and assist with the mission, goals, objectives and values of the PFIC Network.

**Terms:** Board of Directors members will serve for terms of two (2) years. At the end of a term, a Board of Directors member may be invited to serve for another term, with a limit of 3 consecutive terms. After 3 consecutive terms (6 years), a Director must sit off for at least one (1) year before such Director can be re-nominated, re-apply, or be re-elected. The Board may opt to elect a Director for a term of two (2), four (4), or six (6) years to maintain staggered terms on the Board. A member of the Board of Directors may resign by submitting a written notice to the PFIC Network Board of Directors. At any regular meeting or special meeting called for this purpose, the PFIC Network Board of Directors may fill a vacancy on the Board of Directors by selecting a new member.

**Compensation:** Members of the Board of Directors will receive no compensation for their time or their expertise unless otherwise voted on by members of the board and consistent with the bylaws of our organization. Board of Directors members will be reimbursed, however, for expenses that are incurred to fulfill their specific responsibilities to PFIC Network, as long as these expenses are reasonable and appropriate, are authorized ahead of time, and are not covered by other means.

## 3. Director Duties

All board members, regardless of specific role, are expected to participate in the following duties:

## Board Responsibilities and Expectations

- Attend monthly board meetings
- Review agenda and supporting materials prior to board and committee meeting
- Review outcomes and metrics created by PFIC Network for evaluating its impact, and regularly measure its performance and effectiveness using those metrics
- Approve PFIC Network’s annual budget, audit reports, and material business decisions
- Partner with the other board members to ensure that board resolutions are carried out

### 4. Director Responsibilities and Expectations

All board members, regardless of specific role, agree to the following expectations:

As a member of the PFIC Network Board of Directors, I have a legal and ethical responsibility to ensure that the organization does the best work possible in pursuit of its goals.

I believe in the purpose and the mission of the organization, and I will act responsibly and prudently as its steward. As part of my responsibilities as a board member:

1. I will share the organization’s work and values with the community.
2. I will professionally represent the organization and act as an ambassador for the PFIC Network.
3. I will share our constituencies’ needs and values with the organization, speak for their interests, and on their behalf, and hold the organization accountable.
4. I will make a personal financial contribution at a level that is meaningful to me.
5. I will actively participate in PFIC Network’s annual fundraising activities; this means asking my contacts to give to campaigns and cultivating relationships with existing or prospective PFIC Network donors.
6. I will attend at least 75% of board meetings and read agendas and decision making materials prior to the meeting..
7. I will serve on at least one committee when applicable. I will attend at least 75% of the committee meetings for which I serve.
8. I will make every effort to attend PFIC Network major events as an attendee or a volunteer.
9. I will abide by the terms of the PFIC Network Conflict of Interest policy, including disclosing relevant financial interests annually and excusing myself from discussions and votes where I have a conflict of interest.
10. I will stay informed about what is going on in the organization. I will ask questions and request information. I will participate in and take responsibility for making decisions on issues, policies, and other matters. I will not stay silent if I have questions or concerns.

## Board Responsibilities and Expectations

11. I will work in good faith with staff and other board members as partners toward achievement of our goals.
12. I will review and follow to the best of my ability the processes and procedures described in the organization's bylaws and the Board of Directors Governance Manual.

In turn, the executive officers and board president will be responsible to me in the following ways:

1. Monthly board meetings including updates on financial and organizational activities that allow me to meet the "prudent person" standards of the law.
2. Opportunities for discussion with the president and executive director regarding the organization's programs, goals, activities, and status; additionally, I can request such opportunities.
3. Assistance in the execution of my duties by keeping me informed about issues in rare disease and pediatric medical care, and by offering me opportunities for professional development as a board member.
4. A straightforward response to questions that I feel are necessary to carry out my fiscal, legal, and moral responsibilities to this organization. Board members and staff will work in good faith with me toward achievement of our goals.
5. If the organization does not fulfill its commitments to me, I can call on the board president and president to discuss the organization's responsibilities to me.

#### 4. Specific Executive Officer Responsibilities:

Election for executive leadership positions will be held at one of the Board of Directors meetings or at any other Board of Directors meeting in the event of a vacancy in that position.

##### President

- Preside at all meetings of the Board of Directors
- Lead the board in the decision-making process and ensure that all directors are able to express their opinion and contribute input
- Be objective and impartial and not lead the discussion to a predetermined conclusion.
- Meet with the Executive Director on an ongoing basis, a minimum of once per month
- Lead the Board of Directors in the following activities and processes:

## Board Responsibilities and Expectations

- Governance, including maintaining Board structure, following procedure of the Governance Manual and ensuring bylaw compliance
- Organization strategic planning and prioritization of organization strategic goals
- Delegating authority and responsibility to Executive Director and other PFIC Network staff and consultants
- Evaluating strategic results and annual performance reviews
- Designing and implementing an orientation program for new Directors
- Act as or appoint an official spokesperson of the board and staff to media and the public
- Communicate all relevant leadership, governance and strategic information to staff and the Board of Directors
- Ensure the Governance Manual is reviewed and updated regularly and is adhered to.

### Vice-President

Be knowledgeable about and able to fulfill the duties of the President, should the President be temporarily unavailable.

### Secretary

- Record minutes, notes, and action items at meetings
- Ensure all decisions are documented accurately in minutes, relevant policies, and other documents
- Distribute minutes, documents, and notices of meetings to the Directors in a timely mann

### Treasurer

- Work with PFIC Network staff to create and maintain accurate financial records of the organization's funds
- Provide oversight to PFIC Network staff and participate in the internal controls and safeguards established to ensure proper disbursement of organization funds in accordance with the board approved budget
- Review monthly bank statements and reconciliation reports and quarterly financial statements provided by staff
- Assist staff with reporting and meeting all necessary requirements to ensure the organization maintains good standing with the IRS and other applicable agencies
- Overseeing the board's review and action related to the board's financial responsibilities



## Board Responsibilities and Expectations

**I have read and understand this board member contract and have had the opportunity to ask questions.**

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Printed Name

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Signature

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Date