

The PURA Syndrome Foundation



PURA Syndrome Foundation Board Job Description - Secretary Position

The Board of Directors of the PURA Syndrome Foundation is seeking to fill a new position of Secretary of the Board of Directors. The PURA Syndrome Foundation is a global non-profit organisation, registered in the US in 2016. Our mission is to serve, educate and fund research for families coping with the effects of PURA syndrome. Foundation, families, clinicians and researchers together as one community.

Secretary

Job Description overview:

The position of secretary is generally to Coordinate and assist the running of board meetings, organize and document the procedures of the board, and to assist with assignments of tasks of the board and committees.

Additional assistance will be for transparency and accountability of the foundation, including annual reporting. The secretary is expected to have a in-depth knowledge of the organization's articles of incorporation and by-laws, policies and procedures, financial and legal situation, and strategic plan.

Specific responsibilities are expected to include:

- Scheduling Board meetings
- Assisting President with Board Meeting Agenda development
- Distribution of Board meeting agenda and call for meetings
- Taking, distribution, and filing of meeting minutes
- Review filing procedures of the Foundation, with oversight of filing structure for Board and various Committees
- Interface with the Clerk of the Foundation for legal compliance
- Assisting the Treasurer for reporting and auditing purposes.
- Oversight and follow up of Action Items of the Board and Committees (as requested)
- Assisting President with Year End Reporting
- Assisting other officers of the board (as needed)

Qualities of a candidate should include:

- Strong organizational Skills, with ability to understand evolution of projects and organization over time
- Broad cultural perspective
- Ability to communicate, listen, and seek input from others
- Strong group dynamic skills - Ability to work within varied group settings including Foundation Board, and committees
- Understanding of various electronic platforms to assist with reporting and filing responsibilities.
- Multilingual is preferred but not required

Anticipated time commitments:

This is a volunteer position with a 3 year commitment to serve on the Board of the Directors. Travel is encouraged at least once annually to the Annual Conference and possibly a second international trip for planning or other purposes.

Scheduled board meetings take place 9 to 10 times a year via electronic call and are generally 90-120 minutes in length.

10-12 hours monthly commitment should be anticipated on average, with more around the time of the annual conference and year-end reporting.

Interested applicants should contact Dominic Spadafore, President of the Board at: d.spadafore@pura-syndrome.org

Please include SECRETARY in the subject line.

Candidates can anticipate a phone interview with the president and a second voice or video interview with the board. Participation will start with the following board meeting upon accepting of the position.

Additional questions may be directed to Dominic Spadafore.