

PURA Syndrome Foundation



PURA Syndrome Foundation Board Job Description - Vice President

The Board of Directors of the PURA Syndrome Foundation is seeking to fill a new position of Vice President. The PURA Syndrome Foundation is a global non-profit organization, 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.

Vice President

Job Description overview:

The position of Vice President is largely to assist the president with internal affairs and assuring policies are implemented throughout the work of the foundation. Additional assistance will be for transparency and accountability of the foundation, including annual reporting. Advocacy of broad based cultural perspective is important to the success of the position and the foundation. The Vice President is expected to have a working 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:

- Assisting President with “day to day” affairs and running of the Foundation, including managing board meetings and internal communication
- Assisting with development and implementation of board policies and procedures
- Assisting President with Year End Reporting
- Assisting other officers of the board with HR issues (as needed)
- Checking with board members and assisting as required
- Involvement in board committees
- Assisting with public outreach
- Assisting with setup of potential chapters or branches

Qualities of a candidate should include:

- Experience within a global and/or charitable organization is preferred
- Multilingual is strongly preferred
- Legal or financial experience pertaining to non-profit
- Broad cultural perspective
- Knowledge of strategic planning and fundraising
- Ability to communicate, listen and seek input from others
- Strong group dynamic skills - Ability to work within varied groups settings including Foundation Board, committees (both parent and medical) and within the parent group
- Demonstrates community leadership

Anticipated time commitments:

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

Scheduled board meetings take place 10 times a year via secure skype video call. 25-40 hours monthly hours additional monthly work should be anticipated.

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

Please include VICE-PRESIDENT in the subject line.

Candidates should anticipate a phone interview with the president and a second 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.