



Program: PFIC Family Conference

Mission: To provide support in all aspects of our mission

Summary: The opportunity to host an in-person conference consisting of patients, caregivers, families, doctors, specialists, researchers, scientists, industry and biotech

Explanation of Need: PFIC is an ultrarare disease, affecting 1:100,000 patients. Ability to connect with each other and the healthcare community remains difficult due to the diversity of patients. The conference serves as a place to bring together all stake holders, both connecting the dots and bridging the gap amongst the patient and healthcare community.

Description of Program: The PFIC Network will host a weekend long family conference in conjunction with the ALGSA Scientific Symposium. The agenda will consist of opportunities to connect as peers, educational opportunities on key items including treatment options both medical and surgical, research updates, nutritional support and advocacy opportunities. The PFIC Network will collaborate with all stakeholders to provide a scholarship program for attendance. Excess funds may be used to support regional meetings in off years.

Who can volunteer for this program: There will be a planning committee consisting of 3-5 individuals who will be responsible for planning the conference. The chair of the committee will communicate it's needs with the board of directors at monthly board meetings.

Approximate time commitment: The committee will begin meetings in March of 2020 and will meet every other month for 1 hour by phone. Those involved will be expected to stay connected to the program through the conference in June 2021.