Program: PFIC Network Awareness Program

Mission: To provide awareness and advocacy opportunities

Summary: An ongoing program to drive awareness and advocacy efforts and will in turn grow our community and our footprint.

Explanation of Need: There is an urgent need to create opportunities to make the public aware of PFIC and the needs of its patients/families. Without a continue force driving these efforts, information about the disease will not be effectively communicated, and solutions and treatment options will be slow to develop.

Description of Program: The PFIC Network will provide and encourage opportunities to spread awareness for PFIC and its patients. The program will have a committee that will meet monthly to discuss such opportunities and come up with innovative ways to create opportunities and include all stakeholders. Two main examples of these opportunities are Rare Disease Day and PFIC Awareness Day. The committee will also provide mentorship and toolkits to those committed to raising awareness efforts on their own.

Who can volunteer for this program: Anyone with a passion to spread PFIC Awareness can join this program.

Approximate time commitment: The committee will meet every other month for 1 hour by phone. During times of awareness events (Rare Disease Day, PFIC Awareness Day), as many as 1 hour per week may be expected.