



Program: PFIC Network Advocacy Program

Mission: To encourage and participate in advocacy opportunities.

Summary: To build the resources of the PFIC Network and its volunteers. To provide opportunities and encourage patients and caregivers to speak up about the patient experience and their needs as a patient population.

Explanation of Need: The success of the PFIC Network has been driven from community members themselves. In-person meetings and networking are essential and effective ways for our volunteers to grow and develop in their roles. Momentum and passion are ignited in each opportunity to meet with another member of our community, whether it is of the patient community or any of its professionals.

Description of Program: The PFIC Network will sponsor attendance at major conferences including Global Genes, NORD, AASLD, EASL. In addition to participating in these conferences, we will also host poster presentations at a minimum of 2 events. We will also take part in opportunities to travel to regulatory and governing bodies to lend our voice or speak of our needs. We will provide opportunities to engage with local, state, and national policy makers and regulators to promote advancement of PFIC research and treatment options.

Who can volunteer for this program: Any community member (patient, family member, caregiver, supporter, etc) who wishes to join the organization can join the advocacy program. A community member who has been involved with the PFIC Network for a minimum of 6 months can be presented with opportunities to partake in the travel portion of the advocacy program.

Approximate time commitment: Time will vary based on individual needs. Most training or conference attendance will be a minimum of 1-3 days per conference/program.