



Program: Parent Ambassador Programs

Mission: Match Families with peer support, regionally based as possible

Summary: Provide assistance with finding a physician with a knowledge base in PFIC, both adult or child, as well as providing peer support specific to one's geographic location.

Explanation of Need: There is an extreme need for individual peer support and mentorship that only patients or caregivers of the disease can provide based on firsthand experiences. We have recognized the impact of mentors who understand the specific burdens of that population. Not only will mentors be available for support in their own communities, but they will also be able to identify the knowledge and resource gaps that each population may have and work towards finding solutions.

Description of Program: As we connect with volunteers from all over the world, we will identify those individuals or families who are knowledgeable, resourceful, interested in learning and interested in mentoring. We will provide a basic training session over the phone to discuss the capacity in which we may be able to provide assistance and where we may need to defer out. Some needs may not be able to be addressed, but we will continue to communicate those and work on finding solutions. Needs may vary from having a person to share stories to finding a specialist to getting genetic testing done to navigating insurance issues.

Who can volunteer for this program: Anyone who is connected to PFIC as either a parent/patient/family member or supporter. Those interested must be set up to communicate via email, be comfortable communicating with medical professionals and go through a minimum of two 90-minute training sessions in the program. He or she must be dedicated to providing emotional support, at the very least, for those who are struggling with PFIC.

Approximate time commitment: An initial time commitment of two 90-minute training sessions. After initial training, a 1 hour monthly check in with the PFIC Network Peer Support Chair to discuss current resources and needs. Time with mentees will vary based on needs, but a minimum of 1 hour per month per mentee will be expected.