

## **Description and Scope of the Project:**

"It takes a village" is such a common phrase used when it comes to raising children. Families, teachers, coaches, healthcare providers, and community members all play a role in helping children grow into healthy, thriving individuals. Now, imagine raising a child with complex medical conditions (CMC)

Children with CMC often require constant, round-the-clock care. They may be wheelchair-bound, non-verbal, connected to breathing machines, feeding tubes, or central lines. Many are cognitively delayed and will never be potty trained. Simply getting out of bed requires multiple people. Leaving the house demands specialized vehicles and careful planning. Medications and therapies are needed day and night, no matter how exhausted everyone is.

Amid all of this, parents are still expected to work, pay bills, care for siblings, do laundry, cook meals, manage a household and somehow find time to sleep or eat. Social circles often shrink, leaving families isolated in their most difficult moments. A caregiver's health and wellness is put on the back burner and begins to take a serious toll. How can any one person, or even one family, carry all of this alone?

Caring for a child with CMC doesn't just take a village, it takes villages. Families have reported the lack of adequate home nursing. Many can't return to work. Some are struggling to meet even the most basic daily needs. That's why in 2025, PPCC launched the Resource Matching Program (RMP) for families overwhelmed by the exhausting maze of care. We know that resources exist, but they're often hard to find, harder to access, and nearly impossible to manage when caregivers are already stretched beyond their limits.

At the heart of this the RMP is the LANTERN Initiative. LANTERN stands for Listening, Advocating, Navigating, Tailoring, Educating, Referring, and Networking and is fully all driven by compassion. What makes it special? Every LANTERN volunteer is a parent of a child with CMC. They've lived the sleepless nights. They've faced the emergencies, the appointments, the endless coordination. And they are here to walk alongside other families, providing support that is deeply personal.

Navigating care also shouldn't require a binder full of paperwork. The Lightning Bug App that was developed with generous funding from the Women's Board of Pittsburgh has been serving families throughout Pennsylvania for the past six years. With that in mind, we knew that an upgraded digital tool to meet the needs of the families in this new program was needed. PPCC partnered with Thanacare to develop Firefly, a secure, private app that takes everything from our popular Lightning Bug app to help families stay organized in the chaos of caregiving. It lets them store medical records, track medications and appointments, and communicate their child's needs to care teams all in one place. This new iteration of the app, allows LANTERN volunteers and PPCC staff to deliver personalized support and tailored resources directly through the app, giving families help in a quick and easily accessible way. It will also allow for more secure storage of information and provides a safe protocol for transferring information.

The Resource Matching Program and LANTERN Initiative is just getting started and PPCC is excited for its continued growth. To continue building a sustainable program, build more "villages" and to reach more families, we need the continued fiscal support of the community. Donations ensures that these vital tools and peer networks remain free and accessible to the families who need them most. It means no parent has to walk this road alone. It means more families can achieve peace of mind, dignity, and the best possible quality of life in the face of unimaginable challenges.

**What data will you use to measure the success of the program or project goals:**

To measure the success of the Resource Matching Program (RMP) and the LANTERN Initiative, we will collect both quantitative and qualitative data aligned with our goals of easing caregiver burden and increasing access to resources for families of children with complex medical conditions (CMC) and intellectual and developmental disabilities (IDD). Data will be gathered through the use of pre and post-participation surveys, general feedback given in regard to the experience, and participant and volunteer interviews.

We will quantify measurable outcomes in the following areas:

- **Program Reach and Engagement**
  - Number of families enrolled in the LANTERN Initiative
  - Frequency and duration of interactions between families and volunteers
  - Number of resources delivered and referrals provided
  - Website analytics
- **Caregiver Outcomes:** (*measured through pre and post program surveys*)
  - Caregiver-reported stress levels
  - Changes in caregiver confidence navigating systems of care and ability to access needed resources
  - Feedback on feelings of isolation, empowerment, and social support
  - Amount of positive resource connections (was the family able to use/access suggested resources?)
- **Use and Impact of Firefly App**
  - Number of families actively using the Firefly app
  - Number of resources able to be shared via Firefly
  - User satisfaction (as part of post-survey)
  - App analytics (available from Thanacare)
- **Volunteer Impact and Retention**
  - Number of active LANTERN volunteers and retention rates
  - Volunteer satisfaction and feedback (through narratives and volunteer survey)
- **Narrative and Testimonial Data**
  - Personal stories and testimonials from participating families and volunteers

- Case examples demonstrating the program's impact on family life and care outcomes

**How will your organization continue this program after the grant is expended:**

PPCC is deeply committed to the long-term sustainability of the Resource Matching Program (RMP) and the LANTERN Initiative. While initial grant funding has allowed us to launch and pilot these vital services, our plan for continuing the program after the grant period includes several strategies.

We will pursue additional grants and funding from foundations, healthcare organizations, corporate partners, or others that align with our mission to support families of children with complex medical needs. Part of any funding will include continuing to grow and develop the volunteer program that is not only cost-effective but is also rewarding to the members of the community wanting to support this population.

Thanacare (the company that developed and powers Firefly) has been a critical partner in the development of a user-friendly tool for families. Discussions have included concerns over the future funding of this tool. Thanacare is committed to this continued partnership and often seeks funding sources outside of PPCC.

We will continue to collect data on outcomes, satisfaction, and needs to demonstrate the program's effectiveness. Sharing these results with current and potential funders strengthens our case for continued investment and helps secure long-term support.

This program was designed not just as a one-time offering, but as a growing movement of support, advocacy, and resource-sharing. With continued community investment, strong partnerships, and a clear vision for the future, PPCC will ensure that the RMP and LANTERN Initiative remain sustainable and available to the families who need them long after the grant period ends.