Families are left without a clear understanding of the causes, triggers of flares, the natural history of the disease, although, many parents indicated that it took them a long time to trust the healthcare system again, diagnosis.

Relief comes with the ability to match up genetic findings and a cluster of symptoms to a previously-described disease entity.

Patients with rare autoinflammatory diseases of familial Mediterranean fever (FMF), mevalonate kinase deficiency (MKD/HIDS) and familial cold autoinflammatory syndrome (FCAS) report challenges in matching symptoms to disease.

Most parents indicated that they had a hard time recognizing when paediatric illness is "normal" and "normal is different for every child".

Over time, parents said that they had stopped accepting physicians' explanations and start searching for their own answers.

Many parents (generally moms) stated that they began to doubt themselves, and wondered if the symptoms were "real" or if they were imagining things.

"The medical system was like a merry-go-round, endless doctors and tests and drugs but absolutely no resolution." TRAPS patient, age 28.

Parents live in constant anticipation of the next flare or episode, no matter how seemingly successful the current therapy may be.

"I'd like for more research to be done on all the symptoms of [periodic fever]. Research focuses only on the flares but doesn't look at what happens between flares. We don't feel it's ever 100% gone between flares." PFS parent quote.

The patients' ages ranged from 1–28 years. Time to diagnosis of patients ranged from 2.5 to 24 years, with first-time parents indicating that they had a hard time recognizing when paediatric illness is "normal" and "normal is different for every child".

Most parents (92%) lost faith in the medical system's ability to find an answer to their children's symptoms, while 73% still struggle with trust issues.

"I would spend every weekend and every waking moment and stay up all night long looking online for what it would be. I've learned to tell HIDS flares from the flu, but that took quite a while." PFS parent quote.

Parents reported that they were in a constant state of stress, anxiety, and confusion for the patient and their families. Distrust of the medical establishment may persist even after diagnosis.

Parents hold little hope for treating these daily symptoms.

"We're on that medical merry-go-round and I want it to end." PFS patient quote.

"I can no longer tolerate the uncertainty. I can no longer tolerate the fear. I need to know if my pain is real, or if this is all in my head." PFS patient quote.

Parents still struggle with trusting explanations that come from medical professionals.

"...Many times you begin to even doubt yourself and wonder if this is all in your head. Sometimes you wonder if you wondered if you would ever know a day without pain..." PFS parent quote.

During episodes, parents experience a heightened sense of being overwhelmed and out of control.

"My kid was in pain and I couldn't do anything differently. I just had to accept that this was the way things were going to be." PFS parent quote.

For many parents, the uncertainty about the future is emotionally challenging for parents and their children.

"I feel like I am a medical detective, trying to figure it all out. I've learned to tell HIDS flares from the flu, but that took quite a while." PFS parent quote.

Parents felt the need to gather as much information as possible about their children's conditions and therapies to make informed decisions.

"I don't know and I can't predict anything. Not today, not next week, and not in 20 years." PFS parent quote.

"I've learned to tell HIDS flares from the flu, but that took quite a while." PFS parent quote.

"I learned to live with the diagnosis. I have four kids now, and when, after about 10 years, I just felt like my life was over, I decided that I had to make a change." PFS patient quote.

"The uncertainty is the cornerstone of life with PFES." PFS patient quote.

"I can no longer tolerate the uncertainty. I can no longer tolerate the fear. I need to know if my pain is real, or if this is all in my head." PFS patient quote.