



Dear Newly Diagnosed Family,

It's a club none of us wanted to be in. It's also quite frankly the most loving, supportive, community driven group of families you might ever have the pleasure of meeting.

The diagnosis of a CASK gene mutation elicits so many emotions - fear, confusion, grief, worry... Perhaps even a bit of relief to finally understand the underlying cause of your child's problems. At Project CASK, we understand. We are parents who have faced this diagnosis and no matter how much time passes, we all remember diagnosis day.

First and foremost, we want you to know that you are not alone. We are here to listen, provide information, share experiences, and hopefully give you reasons for optimism - whatever you need to help navigate this new journey you and your family are now on. We are part of your team.

Second, we want you to know that Project CASK is passionately dedicated to driving research breakthroughs to find treatments and a cure, enabling people affected by CASK to live a life of independence, free of the debilitating effects of CASK related disorders. Science and technology have accelerated so much in recent years, providing opportunities to develop therapeutics for challenging neurogenetic disorders like CASK. Project CASK aims to explore every potential opportunity, guided by a sense of urgency, a commitment to safety, and a laser focus on efficacy.

There is a beautifully supportive and welcoming CASK community of parents, grandparents, and other family members with arms already outstretched to embrace you. Please reach out when you are ready, we can help introduce you!

***With Warm Regards,
Hitomi Kubo & Renée Roquet***

Project CASK co-founders

hello@projectcask.org

projectcask.org

[@projectcask](https://www.instagram.com/projectcask)