

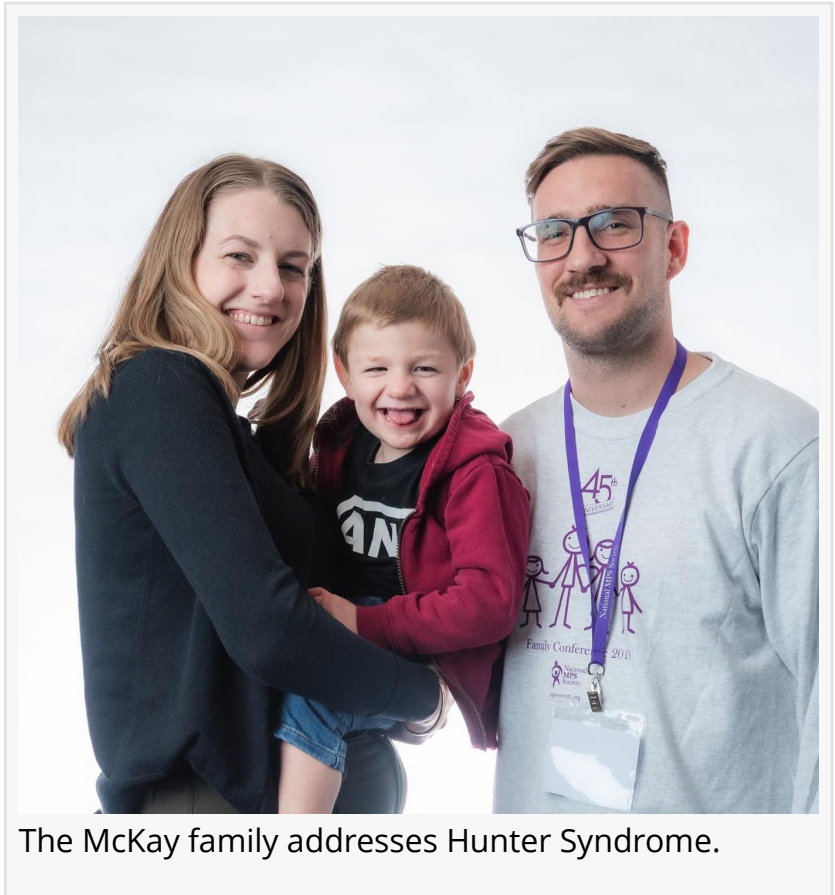
Project Alive Shines a Light on Rare Disease Week and Rare Disease Day to Raise Awareness for Hunter Syndrome

WASHINGTON, DC, CA, UNITED STATES, February 24, 2025 /EINPresswire.com/ -- -- [Project Alive](#), a leading nonprofit dedicated to advancing research and support for individuals affected by Hunter syndrome (MPS II), is joining the global community in recognizing [Rare Disease Week](#) and Rare Disease Day on February 28, 2025. This annual observance brings attention to the 300 million people worldwide living with rare diseases, including those impacted by Hunter syndrome.

Rare Disease Week, held in conjunction with Rare Disease Day, serves as an important platform to highlight the challenges faced by individuals with rare conditions. Project Alive is proud to be part of this international movement, helping to amplify the voices of those living with Hunter syndrome.

Hunter syndrome is a progressive and life-limiting genetic disorder that primarily affects boys, leading to severe physical and neurological decline. Project Alive is at the forefront of efforts to fund cutting-edge gene therapy research, advocate for early diagnosis, and provide crucial support to families navigating the complexities of this rare disease.

“Rare Disease Week is a pivotal time for us to bring attention to the impact of Hunter syndrome and other rare diseases,” said [Kristin McKay](#), President and Executive Director of Project Alive. “By increasing awareness and advocating for research, we move closer to transformative treatments that offer hope to families.”



The McKay family addresses Hunter Syndrome.

Kristin's 6-year-old son Charlie has Hunter Syndrome. Kristin and her husband Matthew recently participated in the Lake Arrowhead Polar Plunge to raise awareness and funds for research.

In honor of Rare Disease Week and Rare Disease Day, Project Alive is launching a social media campaign using #ProjectAlive and #RareDiseaseDay to share personal stories, highlight scientific advancements, and encourage community involvement. Supporters are invited to participate by wearing stripes, a symbol of rare disease awareness, and sharing their photos online.

Additionally, Project Alive continues to push forward with its mission to fund groundbreaking research, including promising gene therapy initiatives aimed at altering the course of Hunter syndrome.

To learn more about Project Alive, support its mission, gene therapy and other novel therapies or get involved in Rare Disease Week and Rare Disease Day activities, visit www.projectalive.org and follow @ProjectAlive on social media.

Media Contact:

Mike Mena

mike@ileanainternational.com

310-913-0625

Michael T Mena

Ileana International

+1 310-913-0625

[email us here](#)

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