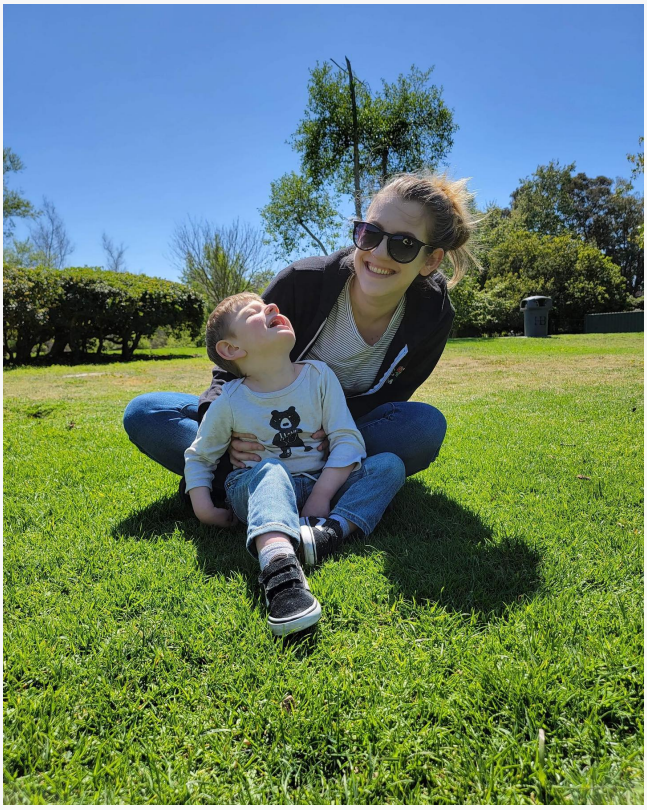
# Raising Awareness for Hunter Syndrome

*Uniting Against a Rare Genetic Disorder*



Addressing Hunter Syndrome, Kristin McKay

REDONDO BEACH, CALIFORNIA, UNITED STATES, September 6, 2023 /EINPresswire.com/ -- -- To shed light on the rare genetic disorder known as Hunter Syndrome, Project/Alive is determined to promote understanding, and support for affected individuals and their families. Also referred to as mucopolysaccharidosis II (MPS II), Hunter Syndrome is a progressive and debilitating condition that primarily affects young boys.

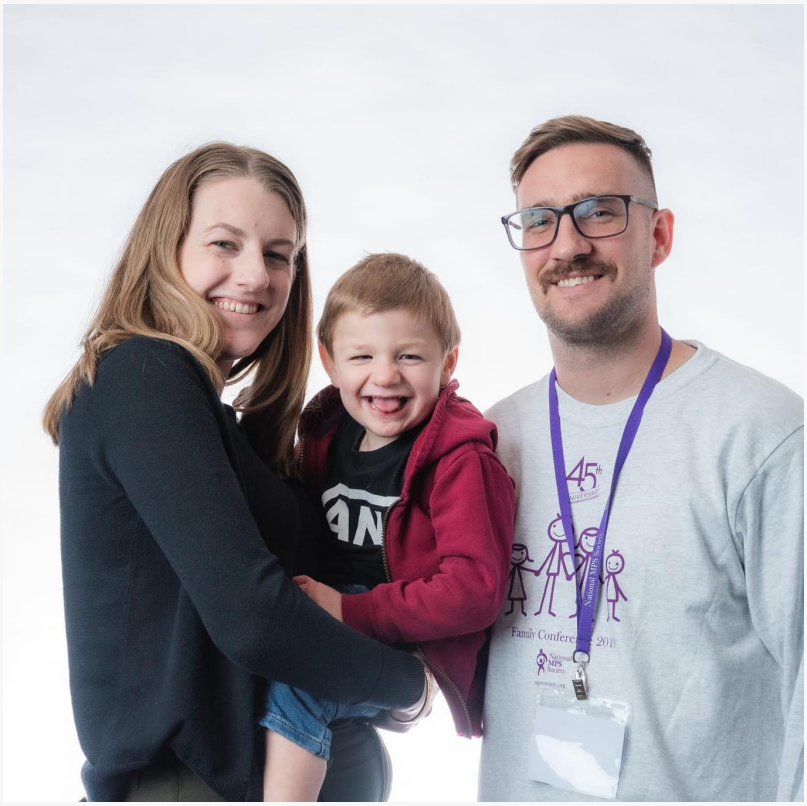
Project/Alive will be hosting a fundraising celebration event at the Hilton Costa Mesa. The festivities include: the Project/Alive Family Fair which takes place from 8:30 AM-2:00 PM. The event also includes a Casino Night which includes a 4:00 PM VIP Cocktail Hour. All events take place on October 28, 2023.

Project/Alive Executive Director Kristin McKay stated: “Raising awareness and funding is very personal for me. My brother Zachary had Hunter Syndrome. He passed away in 2015 at the age of 19. This painful awareness alerted me to the elusive early detection. My beautiful son Charlie is a spark of life and happiness. He’s currently 4 ½ years old. Charlie has Hunter Syndrome.”

Hunter Syndrome is caused by a deficiency of the enzyme iduronate-2-sulfatase, which is crucial for breaking down complex molecules in the body. This deficiency leads to the accumulation of substances called glycosaminoglycans in various tissues and organs, resulting in a wide range of physical and cognitive symptoms. Children born with Hunter Syndrome often appear healthy at birth, but as the disorder progresses, they may experience a variety of challenges, including coarse facial features, joint stiffness, organ enlargement, heart problems, respiratory issues, hearing loss, and developmental delays. The severity of symptoms can vary widely, making early diagnosis and intervention critical for providing affected individuals with the best possible quality of life.

The campaign to raise awareness about Hunter Syndrome aims to:

1. Educate the Public: By providing accurate and accessible information about Hunter Syndrome, the campaign aims to dispel myths and misconceptions surrounding the disorder, fostering understanding and empathy within communities.
2. Empower Families: Families of individuals with Hunter Syndrome often face emotional, financial, and logistical challenges. The campaign seeks to connect these families with resources, support networks, and medical experts to navigate their journey effectively.
3. Encourage Early Diagnosis: Timely diagnosis of Hunter Syndrome is essential for implementing appropriate medical interventions and therapies. The campaign emphasizes the importance of early screening, which can greatly impact the long-term prognosis for affected individuals.



The McKay family addresses Hunter Syndrome.

4. Promote Research: Ongoing research is crucial for advancing our understanding of Hunter Syndrome and developing innovative treatments. The campaign aims to rally support for research initiatives that could lead to improved therapies and potential cures.

5. Foster Global Collaboration: Hunter Syndrome knows no geographical boundaries, and the campaign seeks to foster collaboration between medical professionals, researchers, patient advocacy groups, and policymakers around the world to improve the lives of those affected by the disorder.

Organizations, foundations, and individuals around the world are joining forces to make a difference in the lives of those living with Hunter Syndrome. By raising awareness, supporting families, and promoting research, this campaign hopes to bring hope and change to the Hunter Syndrome community. Project/Alive is an active member of NORD, the National Organization for Rare Disorders.

For more information about Hunter Syndrome and how you can get involved in the awareness campaign, please visit https://projectalive.org/ or contact Mike Mena at Ileana International.

About Hunter Syndrome: Hunter Syndrome, or mucopolysaccharidosis II (MPS II), is a rare genetic disorder caused by a deficiency of the enzyme iduronate-2-sulfatase. This deficiency

leads to the accumulation of glycosaminoglycans in the body's tissues and organs, resulting in a range of physical and cognitive symptoms. Early diagnosis, intervention, and ongoing research are crucial for improving the lives of individuals affected by the disorder.

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