

MPS AWARENESS DAY IS ON WEDNESDAY, MAY 15, 2024 : FOCUS ON HUNTER SYNDROME

LOS ANGELES, CALIFORNIA, UNITED STATES, May 6, 2024 /

EINPresswire.com/ -- [Project Alive](#) is an inspiring source for families and boys affected by [Hunter Syndrome](#). [MPS Awareness Day](#) takes place on Monday, May 15, 2024. Project Alive places a spotlight on MPS also known as Hunter Syndrome, a rare and debilitating genetic disorder affecting young males.

Kristin McKay is the Executive Director for is Project Alive and this is very personal for her. Kristin's brother Zach died from Hunter Syndrome at the tender age of 19. Enduring that enabled her to recognize the symptoms in her son Charlie before he was born. Charlie turned 5 in December.



Charlie McKay celebrates his birthday with his mom Kristin.

MPS Awareness Day serves as a crucial platform to raise awareness about this lesser-known medical condition. The impact on affected individuals and their families is extraordinary. The need for increased research and support is huge and make a tremendous difference in the lives of individuals and families. . Hunter Syndrome, also known as Mucopolysaccharidosis II (MPS II), is a rare disease that demands attention and understanding.

On MPS Awareness Day, Kristin and her son Charlie will travel to Chapel Hill, NC to lobby for Advocacy with Dr. Kim Stephens who also has a son afflicted with Hunter Syndrome advocacy is vital in finding a cure for this disease.

Hunter Syndrome is a lysosomal storage disorder caused by a deficiency of the enzyme

iduronate-2-sulfatase. This genetic anomaly results in the accumulation of certain substances in the body, leading to a range of symptoms such as developmental delays, joint stiffness, and cognitive impairment. The rarity of the disease makes it challenging for affected individuals to access appropriate medical care and support services.

Project Alive is committed to supporting individuals and families affected by Hunter Syndrome. Through advocacy, awareness campaigns, and partnerships with medical professionals and researchers, we aim to bring attention to the unique challenges faced by those living with rare diseases.

For more information about Project Alive initiatives or to get involved, please contact Mike Mena at mike@ileanainternational.com or 310-913-0625

Mike Mena
Project Alive
+1 310-913-0625
[email us here](#)

This press release can be viewed online at: <https://www.einpresswire.com/article/709273553>

EIN Presswire's priority is source transparency. We do not allow opaque clients, and our editors try to be careful about weeding out false and misleading content. As a user, if you see something we have missed, please do bring it to our attention. Your help is welcome. EIN Presswire, Everyone's Internet News Presswire™, tries to define some of the boundaries that are reasonable in today's world. Please see our Editorial Guidelines for more information.

© 1995-2024 Newsmatics Inc. All Right Reserved.