

# RAISING AWARENESS FOR RARE DISEASE DAY: FOCUS ON HUNTER SYNDROME

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[/EINPresswire.com/](#) -- [Project Alive](#) a leading advocate for rare diseases, proudly announces its participation in Rare Disease Day, an annual global event taking place on Thursday, February 29th. The day is usually observed on February 28th except on Leap Year. February 29th is the rarest day of the year. Project Alive places a spotlight on [Hunter Syndrome](#), a rare and debilitating genetic disorder affecting individuals worldwide.

[Kyle Underwood](#) is a Vice President with Project Alive. He will be in Washington, DC to lobby for change and is available for interviews. Today, he will be speaking at two sessions about at the Ronald Reagan Building and International Trade Center.

On Tuesday, he has meetings with members of Congress on Capitol Hill. Kyle has been afflicted by Hunter Syndrome.

Rare Disease Day serves as a crucial platform to raise awareness about lesser-known medical conditions, their impact on affected individuals and their families, and the need for increased research and support. Hunter Syndrome, also known as Mucopolysaccharidosis II (MPS II), is one such rare disease that demands attention and understanding.

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



Project Alive VP, Kyle Underwood goes to Washington, DC to lobby for support for rare diseases day.

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](mailto:mike@ileanainternational.com) or 310-913-0625

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

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