

FOR IMMEDIATE RELEASE:

Prader-Willi Syndrome Association | USA Announces the Resignation of CEO Paige Rivard and Appointment of Interim CEO Stacy Ward

NEWS PROVIDED BY
PWSA | USA

July 12, 2023 – The Prader-Willi Syndrome Association | USA (PWSA | USA) announces the resignation of its CEO, Paige Rivard, MBA. Paige held the CEO position for the past three years and has led many efforts to advance awareness, research opportunities, and provide support for families in the Prader-Willi syndrome (PWS) community. The association extends its heartfelt appreciation to Paige for her leadership and dedication during her tenure.

“In the three years since Paige assumed the leadership of PWSA | USA, the organization has made a lot of progress on all fronts due in large part to her dedication and vision. Paige’s experience as a business leader and as a mother of a child with PWS were of great value to PWSA | USA. Her leadership has been instrumental in shaping the association into the respected and vital resource it is today. We wish Paige the very best in her next endeavor,” said Board Chair Marguerite Rupnow, MBA.

“It has been an absolute pleasure to serve the PWS community and PWSA | USA as the CEO for the past three years.

The organization has grown exponentially in all three of our pillars over these last three years, and a great foundation has been built to continue the important momentum. I would like to thank the staff, Board of Directors, and our community for their commitment to improving the lives of our loved ones living with PWS.

While this decision was not an easy one, I am proud of everyone involved over the last three years, and I look forward to staying involved in other ways within the community and spending some quality time with my family! Remember, together we are United in Hope,” said Paige Rivard.

PWSA | USA will commence a search for a new CEO. In the meantime, Stacy Ward, MS will serve as the Interim CEO, effective immediately. Stacy, who joined the team in August 2016 and has held the position of Family Support Director since December 2017, brings a wealth of experience and a deep commitment to the mission of the association. Her proven track record and passion for supporting individuals with PWS make her an excellent choice to lead the organization during this transitional period.

As the Interim CEO, Stacy will oversee the strategic direction and day-to-day operations of PWSA | USA, working closely with the dedicated staff, volunteers, and board of directors. She is committed to building upon the organization's rich legacy and further advancing its mission to improve the lives of those impacted by Prader-Willi syndrome.

“I am truly honored to step into the role of Interim CEO at PWSA | USA,” said Stacy Ward.
“PWS is a complex disorder that affects individuals and families in profound ways. I am

dedicated to collaborating with the PWSA | USA community to continue to drive positive change, increase awareness, and provide critical resources to empower individuals with PWS to lead fulfilling lives."

Under Stacy's guidance as the Interim CEO of PWSA | USA, the organization looks forward to continuing its vital work, expanding its reach, and providing essential support to individuals with PWS and their families.

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About Prader-Willi Syndrome:

Prader-Willi syndrome (PWS) is a variable, complex rare genetic neurobehavioral spectrum disorder with symptoms resulting from the loss of function of a critical region in the paternally derived 15th chromosome.

Its symptoms vary widely in severity between individuals. Infants have failure to thrive due to feeding problems and hypotonia. Toddlers have increased weight gain. Most of the medical problems in Prader-Willi syndrome are related to obesity, hypotonia, and hypothalamic dysfunction. Other medical complications include high pain tolerance, gastrointestinal and respiratory issues, and difficulty with temperature regulation. Adrenal insufficiency occurs in a small percentage of the population. The most common and challenging symptom among those diagnosed is hyperphagia, insatiable hunger, which can lead to life-threatening obesity which is not responsive to bariatric surgery (PMID: 35416416). The worldwide average lifespan of a person with PWS is 29 years old. Currently, the only FDA-approved treatment for PWS is human growth hormone which was approved over 20 years ago. PWS has no cure.

About Prader-Willi Syndrome Association | USA:

Prader-Willi Syndrome Association | USA was formed in 1975 to unite parents, professionals, and other interested citizens to enhance the quality of life of those affected by Prader-Willi syndrome. PWSA | USA empowers the PWS community through shared experiences, research, education, advocacy, and support. We can't do it alone. We invite you to help us continue to assist our loved ones affected by PWS by making a [donation](#) or learning more about how you can be involved.

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