

EveryLife Foundation for Rare Diseases Announces Departure of Executive Director Julia Jenkins

WASHINGTON, DC, US, October 18, 2023 /EINPresswire.com/ -- The EveryLife Foundation for Rare Diseases has announced the departure of Julia Jenkins from her role as Executive Director, following a successful tenure spanning nearly 15 years. Jenkins will continue her involvement with the Foundation as a board member until January 2024.



During Jenkins' tenure, the Foundation realized a series of significant accomplishments. Notably, she led efforts to promote Newborn Screening RUSP Alignment Legislation in several states, established a bipartisan Rare Disease Congressional Caucus with over 100 Members of Congress, coordinated Rare Disease Week on Capitol Hill, initiated two key studies assessing the economic ramifications of rare diseases, and secured financial resources for both rare disease patients and associated organizations as well as FDA.

Frank Sasinowski, Chair of EveryLife Foundation Board of Directors, noted, "This organizational transition comes as the Foundation approaches its 15th anniversary. With the groundwork laid by Julia, we are poised to continue our trajectory of impact in the rare disease sector. We acknowledge Julia's significant contributions and remain committed to our overarching objectives."

The Foundation will begin its search for a new leader this week, and the Board of Directors has decided to transition the top post from an executive director to a CEO to focus intently on strategy and fundraising. Until the new CEO is named, the Foundation will be co-led by current staff Chief Operations Officer Megan Pinegar and Chief of Policy, Advocacy and Patient Engagement Annie Kennedy.

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EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization

dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures. The Foundation provides training, education, resources, and opportunities to make patient voices heard, help change public policy, and save lives. Learn more: everylifefoundation.org

Margo Metzger
EveryLife Foundation for Rare Diseases
mmetzger@everylifefoundation.org

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