



Vermont Family Network Conference: April 28, 2026
“Pathways Through Change: Empowering Families at Every Stage”



Keynote Speaker Bio:

Jeneva Burroughs Stone (she/her) is an author and advocate for health care and disability rights. While Jeneva has been a writer her entire life, she became a public advocate only after her son **Rob Stone** chose that path in 2018 at transition from high school to adult disability services. That is, Rob took the lead and still does. Rob was inspired to become an advocate in 2012 when he finally received a diagnosis for his ultra-rare disease (DYT-PRKRA) with the help of the [Rare Genomics Institute](#). Since 2019, Jeneva and Rob have delivered remarks at congressional press conferences, at health care rallies, and have testified before the Maryland General Assembly. Rob Stone has recently been quoted in [The New York Times](#).

Rob and Jeneva currently advocate at both state and federal levels. They are members of [Little Lobbyists](#), a national family-led organization advocating for the health care needs of children with complex medical needs and disabilities, and have been tapped to organize the Maryland chapter. They also volunteer for the [Rare Action Network](#), part of the National Organization for Rare Disorders ([NORD](#)); Jeneva is the Maryland Ambassador.

At the state level, the two are members of Maryland's Self-Directed Advocacy Network ([SDAN](#)). They are also members of [Caring Across Maryland](#), a coalition of advocates, workers and patients fighting for a more caring health care system. Jeneva has been appointed by the governor to Maryland's [Rare Disease Advisory Council](#), and, most recently, has been selected for Maryland's [Interested Parties Advisory Group](#), tasked with sharing ideas about the state's HCBS programs. Jeneva and Rob are 2020 graduates of the Arc of Maryland's [Partners in Policymaking Program](#), and advocate frequently on behalf of the Arc.

Jeneva's writing is central to her identity. She's the author of [Monster](#) (Phoenicia Publishing, 2016), a mixed-genre meditation on caregiving, disability & medicine. Her essays & poems have appeared widely in literary journals. She is the recipient of fellowships from MacDowell, Millay Arts, and the Virginia Center for the Creative Arts. Her opinion writing has been featured in [The Washington Post](#) and [CNN Digital](#). You can find more information at her [author website](#).

Born in Burlington, Vermont, Jeneva graduated from CVU and received a BA in English and Creative Writing from Middlebury College. She holds an MFA in Poetry from Warren Wilson and a PhD in English Renaissance Literature from Columbia University. She currently resides with her family in Bethesda, Maryland.