



For immediate release

Contact: Ginger DeShaney  
support@mitoaction.org  
888-648-6228

## MitoAction hosts awareness event featuring Dr. Stepanek

BETHESDA, MD -- MitoAction presents a Mitochondrial Disease Awareness Event in Bethesda, MD, on Sunday, Oct. 6. "Our Dash in Time: Reflections on Dreams and Being," by Dr. Jeni Stepanek, PhD, "Mattie's Mom," will start at 11 a.m. at the Bethesda-Chevy Chase Regional Service Center, 4805 Edgemoor Lane, 2nd floor, Bethesda, MD. To register for this free event, please visit [www.mitoaction.org/stepanek](http://www.mitoaction.org/stepanek).



Stepanek will share her story, her children's stories, and her reflections on lessons she has learned on what matters most about dreams and being as a person who has mitochondrial myopathy.

Mitochondrial disease is an inherited chronic illness that causes debilitating physical, developmental, and mental disabilities. You can be born with it or it can develop later in life. It's progressive and there is no cure. About 1 in 2,000 people has Mito. Symptoms include poor growth, loss of muscle coordination, muscle weakness and pain, seizures, vision and/or hearing loss, gastrointestinal issues, learning disabilities, and heart, liver, or kidney failure. Mito is also related to autism, diabetes, Alzheimer's, and Parkinson's.

Stepanek is the parent of four children – Katie, Stevie, Jamie, and Mattie – all of whom died from Dysautonomic Mitochondrial Myopathy. Stepanek herself was diagnosed with the disease when her youngest child, Mattie, was a toddler. She relies on a ventilator and wheelchair for breathing and mobility, but celebrates life fully.

Mito mom Andrea Smith, who has a daughter with mitochondrial disease, heard about Stepanek when she and her family moved to Bethesda from Texas. She thought having Stepanek speak would create more awareness about mitochondrial disease so she put the wheels in motion for this event.

"She is such an inspiration and powerful life force," Smith said.

An award-winning speaker, writer, and peace advocate, Stepanek is the author of the New York Times Bestseller, "Messenger: The Legacy of Mattie J.T. Stepanek and Heartsongs." Stepanek disseminates inspirational messages about disability, grief, parenting, education, healthcare, collaboration, hope, peace, and spirituality. She earned her PhD and M.Ed. in Early Childhood Special Education, specializing in anticipatory grief and family support. She has a BA in psychology and journalism. She is the Executive Director of the Mattie J.T. Stepanek Foundation, and a Faculty Associate at the University of Maryland. She also serves as a Governor for the We Are Family Foundation and a National Vice President for the Muscular Dystrophy Association and is known as Mama Peace to international youth seeking to make our world a better place.

MitoAction, a Boston-based 501(c)(3) charity, helps families navigate the difficult Mito journey. The organization's mission is improving the quality of life for children, parents, and families affected by mitochondrial disease through free support, education, and advocacy initiatives.

To register, please visit [www.mitoaction.org/stepanek](http://www.mitoaction.org/stepanek). For more information, email Ginger at [support@mitoaction.org](mailto:support@mitoaction.org) or call 888-648-6228.