

Gwendolyn Strong Foundation Awards \$10,000 To Critical SMA Online Support Network

The Gwendolyn Strong Foundation, a Santa Barbara, California based nonprofit organization dedicated to increasing awareness, research funding, and support for Spinal Muscular Atrophy (SMA), the #1 genetic killer of young children, has awarded a \$10,000 grant to Eminnea, Inc., a Maryland based nonprofit organization, for its SMA-space.com project. SMA-space is a critical SMA online patient and family networking resource that was created by Eminnea in 2008 to fill a massive void in access to actionable information and support for patients and families impacted by SMA.

~~Online PR News – 17-June-2010~~ The [Gwendolyn Strong Foundation](#) (GSF), a nonprofit organization dedicated to increasing awareness, research funding, and support for [Spinal Muscular Atrophy](#) (SMA), the #1 genetic killer of young children, has awarded a \$10,000 grant to Eminnea, Inc. (Eminnea), a Maryland based nonprofit organization, for its [SMA-space.com](#) (SMA-space) project. SMA-space is a critical SMA online patient and family networking resource that was created by Eminnea in 2008 to fill a massive void in access to actionable information and support for patients and families impacted by SMA.

"As a family navigating the life-altering impacts of an SMA diagnosis, we are unbelievably grateful for the support and actionable resources that SMA-space provides to the SMA community," said Victoria Strong, GSF co-founder. "Through SMA-space, Eminnea has created an open, unbiased forum for families and medial professionals to share information and we are honored to help support their plans to continue innovating the SMA-space.com experience, believing that immediate access to critical care information, finding support from others in varying stages along the same path, and having the opportunity to connect with SMA experts only provides a higher quality of life for the thousands of children debilitated by this disease."

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While SMA kills more infants and young children than any other genetic disease, many medical professionals are not adequately knowledgeable about the full spectrum of SMA care options, thus are unable to provide families with effective techniques that are available to manage the degenerative nature of the disease. SMA-space has brought thousands of families across the world affected by this cruel disease together to better navigate the very delicate, time sensitive nature of caring for an SMA child. SMA-space is often the only opportunity for these families to meet others with the same diagnosis, speak with SMA experts experienced in the nuances of SMA care, learn about critical equipment shown to lengthen and improve quality of life, and master how to provide quality care for their children.

"SMA space exists for the sole purpose of supporting families impacted by SMA," said Nate Lee, Eminnea co-founder. "We do not focus on fundraising and we do not focus on research - just families - and the Gwendolyn Strong Foundation has been an incredible and encouraging partner in this mission. Not only does this grant confirm the importance of family support programs, but it gives Eminnea tremendous confidence and energy to press on enhancing and developing much needed resources for the community. Over the next few months we will be using these funds to focus on providing SMA space in numerous languages and applying new design and organization for easier navigation."

SMA is a terminal, degenerative genetic disease that impacts the voluntary muscles in infants and children, including the ability to walk, sit, stand, eat, breathe, and even swallow. Ninety percent of children born with SMA die before the age of two. One in 40 people, or nearly eight Million Americans, unknowingly carry the gene responsible for SMA. SMA is currently incurable, untreatable, terminal and underfunded.

About Gwendolyn Strong Foundation (GSF) – GSF is a 501(c)(3) public charity based in Santa Barbara, California dedicated to increasing global awareness of Spinal Muscular Atrophy (SMA), the #1 genetic killer of infants and young children, and accelerating research toward a cure. To learn more about SMA and GSF, please visit <http://GwendolynStrongFoundation.org> or contact GSF at (805) 679-1679.

Image Gallery



Gwendolyn Strong Foundation

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