



FOR IMMEDIATE RELEASE

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New Non-profit Organization Formed in Nashville Brings Attention to a Very Rare Disease "NBIA"

Synopsis:

New charitable organization formed in Nashville brings attention and awareness to the rare disease "*NBIA (Neurodegeneration with Brain Iron Accumulation)*" The funds raised will provide much needed resources to a young woman 29 years old afflicted with the disease and provide funds for research in finding a cure for this rare, real life threatening disease.

NASHVILLE, TN - The Dana Jones Foundation, Inc. was recently recognized by the Internal Revenue Service as a 501 (c) (3) Public non-profit. The charity, based in Mount Juliet, TN was created to raise money for much needed assistance in Dana Jones' daily life and to help slow down, if not regress the onslaught, as her disease consumes her body. "We are also funding research for a cure, so that other individuals will not suffer or endure what Dana has been through," said Mrs. Ronda Jones, Dana's mother. "It is our belief that the foundation will become the legacy for Dana," says Mrs. Jones.

Atypical PKAN Disease

Dana, who is now 29 years old was diagnosed at the age of 16 with Atypical PKAN (Pantothenate Kinase-Associated Neurodegeneration) - a rare form of NBIA (Neurodegeneration with Brain Iron Accumulation). Children with PKAN typically manifest gait abnormalities around age three years and develop progressive dystonia, dysarthria, rigidity, spasticity, hyperreflexia, and extensor toe signs.

About Dana Jones

The first signs actually started when she was just 6 but it took 10 years to finally be diagnosed. Prior to the disorder's onset, she bowled on a team in a local league, was a member of the Girl Scouts of America, and for 4 years played the flute in her high school marching band. For the past 12 years the disease has slowly taken over Dana's body, the ultimate outcome is not encouraging, and without a cure...her life expectancy is in question.

Frustrated, her family has exhausted all efforts seeking out the best medical care possible. She has seen doctors at Vanderbilt Medical Center in Nashville and has recently been accepted for a trial drug program at UCFS Benioff Children's Hospital based in Oakland, California under the direction of Dr. Elliott Vichinsky, a renowned disorder specialist. Dr. Vichinsky recently joined the Dana Jones Foundation as a Board Director and Medical Advisor.

The medicine is called [Deferiprone](#), and has been shown to have the ability to pass through the blood-brain barrier and remove the accumulation of heavy metals such as iron. If the program shows promise for the disease, Dana will have free access to the medicine for the rest of her life.

The Dana Jones Foundation

"Over the years we have struggled with what is best for Dana, and her future," says Mrs. Jones. My sister's husband, Paul Willies offered to establish the foundation as a means to put some meaning behind this grim story. Last summer we started the process of forming the foundation. Paul launched an appeal on Go Fund Me (www.gofundme.com) to raise the initial money for the set-up costs. We successfully raised \$2,835 with the help of our family and friends. However, everything went into limbo until now, finally getting the IRS approval for our 501 (c) (3) Public Non-Profit status. This was the kicker we needed to get going," said Mrs. Jones.

In this past month Mr. Willies, Chief Executive Officer for the Dana Jones Foundation has moved into high gear. He has introduced Dr. Elliott Vichinsky to the board of five directors and also obtained the services of Michael McKerley, PA of McKerley & Noonan, P.C. in Nashville as the organization's accountants.

"We are now registered with www.GivingMatters.com of the Community Foundation of Middle Tennessee, which provides transparency to non-profits in the community," said Mr. Willies. "We are registered to join in with the Big Payback Day scheduled for May 5th, 2015." www.GuideStar.org a national registry of non-profits in the United States, also recognizes the organization.

"Our objective is to raise \$500,000 in the next year through individual donations, corporate giving and grants," said Willies. Our first immediate goal is a wheel chair van for Dana.

For more information or to contribute a tax-deductible donation, visit www.danajonesfoundation.org

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For privacy, please do not contact Dana Jones directly. For scheduling interviews, and further comments please contact Paul Willies, CEO Toll Free 888-683-7538.

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