

WOMEN of DISTINCTION

HEROES



Lori Sames – Hannah's Hope Fund

Exactly two years ago, we were told our precious Hannah, who had just turned four, would die in her late teens or early twenty's as a quadriplegic, dependent on a feeding tube and ventilator. After pulling ourselves from an unimaginable place, my husband, Matt, and I decided to take action. As with any disease, someone has to be the first to be cured—for Giant Axonal Neuropathy (GAN) it will be Hannah.

Because GAN is very rare, little research had occurred. GAN doesn't attract the attention of pharmaceutical companies nor biotechnology companies due to smaller profits. We learned the rare disease community is often left the burden of raising money to fund research to save their loved ones. We formed a 501c3 public charity called Hannah's Hope Fund to raise money and bring the scientific community together to develop a treatment for GAN.

Today, we are planning a clinical trial for the fall of 2011 to save the lives of children world-wide suffering from GAN.

Hannah's Hope Fund just completed a six month



challenge grant from Doris Buffett's Sunshine Lady Foundation. She agreed to match up to \$500,000. Family, friends, and total strangers helped us raise \$620,000 in six months! All funds raised thus far are going toward required safety and efficacy studies in order to gain FDA approval to begin a clinical trial. Monies raised over the next two years will be used to pay for children to be treated during the clinical trial. Clinical trials are considered experimental and thus are not covered by insurance.

I went from a stay-at-home mom to coordinating an international team of scientists working on a treatment for GAN, almost overnight. I am the executive director and work full-time, in-kind, for Hannah's Hope Fund. I am forever connected with the rare disease community. Once we have a successful FDA approved treatment for GAN, I will continue to help other disease communities achieve successful treatments. There is really little else in life that matters when children are dying from ravaging disorders that are treatable given attention and funding. Please visit www.hannahshopefund.org to learn how you can help.