



Austin 1<sup>st</sup> Foundation, Inc.  
EIN 83-4252915

Dear <name here>,

The Austin 1<sup>st</sup> Foundation was founded in April 2019, with a mission to be Champions for Rare Disease by helping raise awareness, research dollars and resources for children and families in Alabama and beyond. The organization was co-founded by Anthony and Lindsey Terling, parents of Anthony 'Austin' Terling Jr., whom the foundation is named after. Austin's story is a rare one. Austin was born June 27, 2013. Through the help of GeneDx, the Undiagnosed Disease Network and UAB geneticist, the late Dr. Lane Rutledge, he was diagnosed a few years later with an ultra-rare genetic condition that effects his UBA5 gene. His prognosis is very life-limiting based on expected decline of his illness; he requires 24-hour home medical care. Many others with rare disease face similar challenges. The UBA5 gene mutation, like many others, effects very few people but the fight for the entire rare disease community is enormous. Below, are a few statistics from the National Institutes of Health on rare diseases.

- 1 in 2 patients diagnosed with a rare disease are children.
- Rare diseases impact more people than AIDs and cancer combined.
- 1 in 10 people are affected by rare disease.
- 1 in 2 rare diseases don't have a foundation or research support group.

We are asking you to join our team in fighting rare disease by contributing to the Austin 1<sup>st</sup> Foundation as a **Founding Partner**. Your generous contribution will help us get started in achieving our mission of creating a savings fund for research, giving Christmas gifts and blankets and booties to Children's Hospital of Alabama, and providing family support resources for medical equipment and other necessities. We are working with UAB Genetics, to gather more resources on rare disease and the UBA5 gene mutation, and are enrolled in a research study at Boston Children's Hospital to determine where our research dollars will go. **Founding Partners**

#### **Donation Levels**

**Champions for Austin** – \$1,000 will be listed on the Foundation's website, Facebook page ([www.austin1stfoundation.org](http://www.austin1stfoundation.org)), and at any future fundraising events (i.e. Aces Fore Austin golf tournament, awareness walk, etc).

**Austin's Heroes** - \$500 will be listed on the Foundation's website

If you cannot be a Founding Partner, but wish to donate, any amount will be appreciated and helpful to achieve our mission. All donations all tax deductible to the extent allowed by law. Online donations can be made at our website. The enclosed card will show what we've accomplished so far.

Sincerely,

Anthony and Lindsey Terling  
Co-Founders - Austin 1<sup>st</sup> Foundation  
Parents of Austin – UBA5 Warrior

*RESEARCH - AWARENESS - SUPPORT - CHANGE*

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