



March 2019

Dear Prospective Supporter,

You are invited to attend the 8th Annual Rylie's Angels A-T Golf Tournament (www.atcp.org/RahallGolf) in association with the A-T Children's Project, which will be held at Dove Canyon Country Club on Monday, June 3, 2019. We are so grateful for the 240 participants who attended last year's tournament and to the sponsors, donors and volunteers who made the tournament possible.

Eight years ago, Rylie Rahall, a sweet, nine-year old angel was diagnosed with ataxia- telangiectasia or A-T, a rare genetic disease. A-T combines the worst symptoms of muscular dystrophy, cerebral palsy, cystic fibrosis, immune deficiencies, and cancer. A-T usually attacks in early childhood and is degenerative, affecting the immune system, nervous system, and brain; and children with A-T are predisposed to fatal cancers, like leukemia and lymphoma. Children with A-T are usually confined to wheelchairs by age 10 and often do not survive their teens. We are racing against time to save our precious Rylie, and we need your help. Rylie has been needing more physical support and usually rides around in her adaptive stroller at school and around the community. She has passed her electric wheelchair training and she will hopefully have her "first set of wheels" by summertime.

Because A-T is a multi-system disease, scientists believe that A-T research will help more prevalent diseases such as Alzheimer's, Parkinson's, AIDS, and cancer. The A-T Children's Project will utilize a significant portion of the funds raised from the tournament toward the gene therapy approach called "antisense oligonucleotide" or "ASO" therapy. This approach has been tested in a lab and has shown that it produces the functional ATM protein that is missing within the cells of children with A-T! In the coming months, for the first time ever, an 18-month-old A-T child will receive the ASO therapy. If this therapy proves successful, it will pave the way for this approach – and other gene therapy approaches – to be used in other A-T children, including Rylie, and result in a **CURE** for A-T. This is the miracle, we as parents, have been hoping and praying for since Rylie's diagnosis. We have wanted nothing more than to give our daughter the chance to live a long, full life, not one that could be cut dramatically short because of faulty genes.

Rylie recently completed the "clinical" portion of a drug trial at UCLA where she receives a monthly infusion. The infusion is comprised of her own blood and a high dose steroid drug to help improve her balance, walking, and speech. We have seen Rylie's A-T progression slow down while she has been receiving the drug. The side effects are minimal compared to the typical side effects associated with taking a steroid.

Please join our family as one of Rylie's Angels and give this child and other children with A-T a chance to live a longer, better life. Whether you participate as a golfer, join us for dinner, sponsor the tournament, donate a product for the silent auction or send a donation, your generosity will help find a cure for A-T. The A-T Children's Project is a 501c3 nonprofit organization and their tax number is **65-0427215**.

With Gratitude, Tim & Erica Rahall

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Silent Auction Donation Form

Publish Name As: _____

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Authorized by: _____ Date: _____

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**To participate as a golfer, join us for dinner, sponsor the tournament, donate a product for the silent auction or send a donation please visit:
www.atcp.org/rahallgolf**

For questions about the tournament, please call or email Tim Rahall at 408.896.6220 or Tim.Rahall@ey.com or Erica Rahall at 949.246.1198 or erica.rahall@gmail.com

