

# Every Inch Counts: James' Scramble for a Cure Golf Tournament Benefits Rare Gene Therapy Research

*Annual Golf Tournament & Evening Gala Benefiting CNTNAP1 Gene Therapy Research*

RANCHO SANTA MARGARITA, CA, UNITED STATES, June 24, 2026 /EINPresswire.com/ -- The Hereditary Neuropathy Foundation (HNF) is proud to announce James' Scramble for a Cure, a charity golf tournament and evening fundraising event to be held on Friday, August 14, 2026, at Tijeras Creek Golf Club, 29082 Tijeras Creek, Rancho Santa Margarita, CA 92688. All proceeds will benefit groundbreaking [CNTNAP1](#) gene therapy research.

## [Event Details](#)

On the Course (Golfers):

11:00 AM – Registration & Lunch Opens

12:30 PM – Putting Contest

1:00 PM – Shotgun Start

Evening Event (Families Welcome):

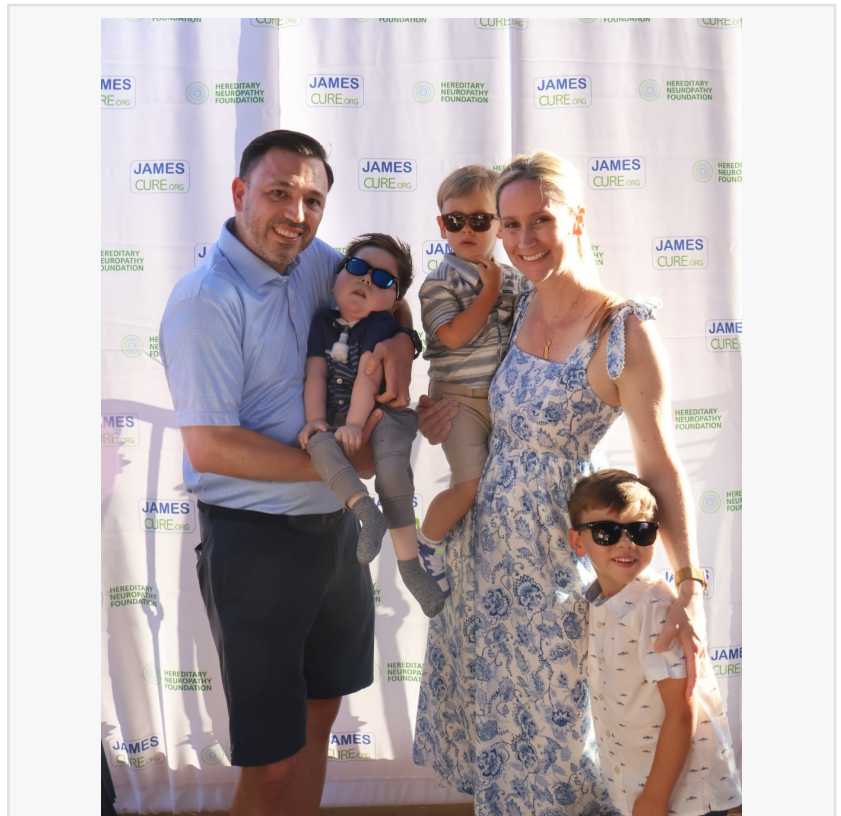
6:00 PM – Dinner, Auction, Awards & Live Entertainment

6:30 PM – Helicopter Golf Ball Drop

7:30 PM – Silent Auction Closes

Tickets and sponsorship opportunities are available at

<https://JamesCure.GiveSmart.com>.



The McCarthy Family



**HEREDITARY  
NEUROPATHY  
FOUNDATION**

## Meet James McCarthy

James McCarthy is an 8-year-old boy living with an extremely rare genetic mutation of the CNTNAP1 gene. From the moment he was born unable to breathe and was immediately intubated, James' family knew his journey would be extraordinary. After spending nearly a month in the NICU at Children's Hospital of Orange County, James was diagnosed with bilateral vocal cord paralysis, hypotonia, and numerous other challenges. Within his first weeks of life, he underwent tracheostomy and gastrostomy tube surgeries.

Today, James uses a wheelchair and is nonverbal, but his family celebrates every "inch stone" he achieves. Through dedicated therapies, he has learned to swallow, move his limbs, smile, and recently began communicating using eye-tracking technology. Over the past year and a half, his health has improved significantly and his family has witnessed remarkable developmental and social growth.

"We pray for a day that we can hear our sweet boy cry or laugh," his family shares. "We are hopeful that with consistent therapy and research, James will continue to have inch stones that we can celebrate."

## About CNTNAP1

CNTNAP1 is an extremely rare genetic disorder in which recessive mutations cause the loss of the gene's protein product, CASPR, disrupting the myelinating cells from nerve cell axons. This results in profound demyelination and weakness affecting both the central and peripheral nervous systems — making it one of the severe CMT (Charcot-Marie-Tooth) syndromes. There is currently no cure.

James' family and the HNF believe gene therapy represents the most promising path forward. Researchers have made significant progress and are actively pursuing gene therapy studies for CNTNAP1.

## About the Hereditary Neuropathy Foundation (HNF)

The Hereditary Neuropathy Foundation is a global nonprofit organization dedicated to improving the quality of life for people living with CMT disease and accelerating research toward treatments and cures. Through innovative research initiatives, patient-centered clinical trial readiness programs, regulatory engagement, and community education, HNF bridges science, industry, and patient voice to drive measurable impact in CMT drug development.

## How to Support James' Scramble for a Cure

- Register to golf or attend the evening event
- Become an event sponsor
- Donate an auction item
- Make a direct donation

Visit <https://JamesCure.GiveSmart.com> to register, donate, or learn more.

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