

Take Part Foundation Launches New Initiative to Support Gould Syndrome Research

Nonprofit sets out to raise \$115,000 to support research from University of California, San Francisco geneticist Dr. Douglas Gould

ST. LOUIS, MO, UNITED STATES, March 10, 2025 /EINPresswire.com/ -- The Take Part Foundation, a St. Louis-based 501(c)(3) nonprofit that identifies and funds medical research for rare pediatric conditions, announced their



The Take Part Foundation is a St. Louis-based 501(c)(3) nonprofit that identifies and funds medical research for rare diseases.

new research project today, providing critical funding support for Gould Syndrome research. The funding will assist geneticist Douglas Gould, PhD, and his research team at the University of California, San Francisco (UCSF) as they work to learn more about Gould Syndrome and potential

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Douglas Gould, PhD

treatments. Through this partnership, Take Part seeks to positively impact the lives of families and children with the rare disorder.

The Take Part Foundation supports families with the cost of genetic testing, raises awareness and develops research projects with measurable goals to advance treatments for rare diseases. Following the success of fully funding a \$280,000 research project for PYROXD1, founders Matt

and Maria Granados—parents to Natalie, who was diagnosed with PYROXD1 in 2021—launched their second research project to support Gould Syndrome. Their decision to focus on this disorder for their next research project was inspired by a St. Louis family navigating its challenges.

Three-year-old Landon was diagnosed with Gould Syndrome by St. Louis Children's Hospital at just one and a half months old after undergoing genetic testing. Gould Syndrome, discovered in 2003 by Dr. Gould, is caused by genetic mutations, which lead most commonly to stroke and eye defects, followed by kidney and muscle abnormalities, according to UCSF.

"When I first learned Landon had Gould Syndrome, I took time to grieve, but then I knew I

wanted to help advance research and raise awareness in any way I could," said Courtney Woods, mother to Landon. "You can't control the diagnosis, but there are other ways you can make an impact."

Woods discovered Dr. Gould as a leading researcher and, inspired by his work, launched efforts to fund research through Landon's Lap, an annual walk/run for awareness and support. It was around this time that she also became connected to Maria Granados of the Take Part Foundation.

"It has been amazing to see what has been accomplished working with Dr. Gould and Take Part to raise awareness," said Woods. "Sharing our story makes a difference, even if it's a rare disease not many people know about—there are so many families we can help."

"We are incredibly excited to be working with the amazing research team under Dr. Gould to help families like Courtney's learn more about what their children are facing and develop potential treatments to help them thrive," said Maria Granados, cofounder of the Take Part Foundation. "We hope to add many more research



The Woods Family. Three-year-old Landon was diagnosed with Gould Syndrome at just one and a half months old.

projects in years to come, expanding our reach to help rare families across the country fight for possible."

To date, The Take Part Foundation has contributed \$20,000 toward Gould Syndrome research and remains dedicated to reaching its \$115,000 goal. The nonprofit raises funds through a variety of initiatives, including its signature gala, Wine Women & Shoes, which will take place in St. Louis on May 1, 2025.

"This collaboration with Take Part not only accelerates our efforts to uncover the complexities of this rare disorder but also brings us closer to a future where families can access specialized medical care tailored to their needs," said Dr. Gould. "Together, we are paving the way for hope and tangible outcomes for those impacted by Gould Syndrome."

To learn more about how to "take part" in the lives of children with rare pediatric diseases like Gould Syndrome, please visit https://take-part.org/.

About the Take Part Foundation

The Take Part Foundation is a 501(c)(3) nonprofit dedicated to helping children with rare and undiagnosed diseases thrive. Too often, the research needed to advance life-altering therapies

for children with rare conditions lacks adequate funding. Take Part funds research, provides resources for rare and undiagnosed families to better tell their stories and assists with access to genetic testing needed for a diagnosis. The nonprofit was founded by Matt and Maria Granados, parents of Natalie, who suffers from a rare genetic disorder, PYROXD1. The foundation empowers families of children with rare diseases, allowing anyone to "take part" in fighting for what's possible. Learn more at https://take-part.org/.

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