Fighting to Find a Cure
for Coats’ Disease

The Jack McGovern Coats’ Disease Foundation was established in 2006 by the parents of Jack McGovern, who, at age 11, was diagnosed with Coats’ Disease. Jack has gone on to become an active athlete, playing football and lacrosse in high school and lacrosse for four years at the collegiate Division 1 level.

Since then, the Foundation has grown to become the preeminent resource for Coats’ Disease patients and their families around the world. We serve as the hub for the Coats’ Disease community; we provide information about specialists who treat this rare disease and to raise funds for research that leads to better treatments and a cure.

What is Coats’ Disease?

Coats’ Disease is a rare eye disorder in which there is abnormal development in the blood vessels behind the retina. The blood-rich retinal capillaries leak blood into the back of the eye. The leakage causes the retina to swell and can cause partial or complete retinal detachment. Coats’ Disease is seen predominately in males (69-75%) and symptoms generally appear in children aged six to eight, but can develop as young as four months.

Coats’ Disease is almost always unilateral (impacting only one eye). If caught early, some level of vision can typically be restored. If caught in late stages, complete loss of vision can occur. In its final stages,enucleation (removal of the affected eye) is a potential outcome. In the U.S., a rare disease afflicts fewer than one in 200,000.

Be on the lookout! Because the fluids are leaking behind the retina, there is often an indicator that shows up in flash photography - the iris may look yellow or white instead of the “red eye” that cameras sometimes capture. This unusual reflection can be an indicator of nearly 20 eye disorders and should be checked immediately by an ophthalmologist.

Patients & Families

Our international Patient Registry is used by researchers to access data about Coats’ Disease and develop better treatments that will limit vision loss and ultimately restore vision. We encourage all patients to add your information to the Registry so we can create a robust resource for researchers that leads to a cure. The essential element of research to find a cure is for researchers to have access to data, tissue samples, and other information to determine genetic markers, inherited characteristics, or physiological patterns that point to Coats’ Disease.

Our international Doctor Directory identifies knowledgeable retinal specialists with experience in treating Coats’ Disease. Nominate your physician to help other patients and their families around the world identify qualified Ophthalmologists who treat Coats’ Disease.

Connect with other Coats’ patients and their families through our website and on social media. Sign up for email updates and our e-newsletter at www.coatsdiseasefoundation.org.

Physicians & Researchers

We encourage doctors who are experienced in treating Coats’ Disease to register with our online Doctor Directory. This will enable patients to globally locate an expert retinal specialist in their part of the world.

Our international Patient Registry is the only collection of its kind that contains a growing database of patients with Coats’ Disease.

We provide Research Funding, including the first-of-its-kind Jack McGovern Coats’ Disease Foundation National Tissue Biobank with the Wilmer Eye Institute at Johns Hopkins to provide resources and data that will lead to enhanced treatments and to a cure.

Research Grants and Educational Travel Grants are available to those interested in studying the causes and treatments of Coats’ Disease and to find a cure. Contact us for more information.
THE FACES OF COATS’ DISEASE

Oliver
“I am so proud of our little man, he nev- er lets Coats’ get in his way. He is three now and he can be a little clumsy at times. He forgets he can’t see things coming from his right when running about, so lamp posts and doors can sometimes pose a hazard. But, other than that, you would never know about “what if we come to the stage where it can’t be managed anymore, and he has to have his eye removed?” How do you deal with that in a child? But we will deal with it, because we will have no choice.”

Andreas
“After performing test after test, and ruling out other possibilities, it was de- termined that Andreas had Coats’ Dis- ease. I’d never heard of it before that point. It was determined that he was at a stage 5, and to prevent further damage to the eye, and to hopefully save the eye, he was scheduled for surgery immediately. Over the course of the year, An- dreas had 9 surgeries to his eye. Because the disease was so advanced, they were not able to restore his vision in that eye, but they were able to save the eye itself.

We are currently 5 years post his last surgery, and just had our final appointment last week with his surgeon. Things are looking as great as they will be considering the stage we were when he was diagnosed.”

Trystn
“Trystn has had two surgeries and so far they have helped tremendously, but we have a very long road to go. He is in the third stage of Coats’ Disease borderline 3b and he has a lot of scar tissue causing the retina to not reattach.

Trystn looks like a normal kid and is very brave! He normally doesn’t let his eye bring him down. Sometimes it bothers him a lot but it’s mainly because he doesn’t understand, being that he just turned 5. I know he will do great things, even with one good eye.”

Contributions will be used to support the charitable activities of the Jack McGovern Coats’ Disease Foundation. The Foundation is a qualified not-for-profit public benefit charity corporation under IRS Code Section 501(c)(3). Our tax payer ID number is 26-2439083.

For more stories like these, or to submit your own, please visit www.coatsdiseasefoundation.org.

Our Four Pillars

Raising Awareness
Increasing awareness of Coats’ Disease is an extremely important part of our mission. We want our community to spread awareness about Coats’ and other rare retinal diseases. The more people who know about Coats’ Disease, the more education, support, and research can be accomplished for children and adults to live happy, full lives. We continue to spread awareness through national and local events, an annual golf outing fundraiser, an annual Cure Coats Run, various digital and social media platforms, interactions with patients, collaboration with physicians, community partners, and face-to-face meetings across the U.S. and internationally.

Funding Research
With a $50,000 donation to the Wilmer Institute at Johns Hopkins, we established the first-of-its-kind Jack McGovern Coats’ Disease Foundation National Tissue BioBank to promote research on the causes and treatments to find a cure. We fund opportunities to facilitate research on Coats’ Disease, including travel grants and collaborative opportunities for specialists and researchers. We have provided grants to the San Francisco Retina Foundation to fund conferences of retinal specialists from around the globe to share best practices and the latest treatment options and studies and to Genentech for a cutting-edge project to explore the DNA of Coats’ Disease. The Foundation provided its first academic grant to Dr. Michael Trese who is researching the origins of Coats’ Disease and sponsored Dr. Michael Junger, an expert in Coats’ Disease, as the keynote speaker on Coats’ Disease at the 2019 Advances Pediatric Retina Conference. We have also established a Scientific Advisory Board, composed of top retinal specialists and researchers in the field.

Building Coats’ Patient Resources
We are the only organization that is dedicated to Coats’ Disease. We are the preeminent source for patients and families to learn about this disorder, receive updates on the latest research, connect with others in the Coats’ Community, and access resources to support patients and families. Our Doctor Directory is the only listing of ophthalmologists who are experienced in treating Coats’ Disease. We developed Frequently Asked Questions and a list of Questions to Ask Your Doctor that patients can take to their doctor to fully explore the implications of a Coats’ Disease diagnosis. We connect the Coats’ Community through our website and social media channels so that each patient and parent knows that they are not alone in facing this rare disorder.

Raising Funds for Research
We raise funds to fulfill our vision of finding a cure for Coats’ Disease. Your donations enable us to:
• Provide grants for research to improve treatments & find a cure;
• Endow scholarships to Ophthalmologists to inspire them to specialize in Coats’ Disease;
• Maintain a comprehensive Doctor Directory of specialists;
• Sponsor events to raise awareness and educate physicians, researchers, and students;
• Engage a network of volunteers around the world to help us achieve our mission; and
• Establish travel grants for researchers to promote research and education.

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Make a Gift

Thank you for supporting the Jack McGovern Coats’ Disease Foundation!

Your tax-deductible gift enables us to continue our relentless efforts to find a cure for Coats’ Disease.

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Donate Online at www.coatsdiseasefoundation.org