

# Jack McGovern Coats' Disease Foundation

## Press Kit



**Coats' Disease Foundation**

[www.curecoats.org](http://www.curecoats.org)



# Who We Are

The Jack McGovern Coats' Disease Foundation was founded in 2006 by the parents of Jack McGovern as a promise to their 11-year-old son, Jack, that they would never rest until there was a cure for Coats' Disease.

We are the only Foundation dedicated solely to Coats' Disease. Our *Mission* is to raise funds to support research, raise awareness, expand patient resources, and offer all Coats' Disease patients hope and improvements as they wage a lifelong battle against Coats' Disease and blindness.

All our efforts are focused on:

- Raising Awareness
- Funding Research
- Building Patient Resources

Coats' Disease is a rare disorder characterized by abnormal development of the blood vessels in the retina. In Coats' Disease, the blood-rich retinal capillaries leak fluid into the back of the eye. The leakage causes the retina to swell and may lead to partial or complete retinal detachment, which can cause vision loss or the loss of an eye. Coats' Disease primarily afflicts children.

There is no cure. Coats' Disease is a lifelong disease.



Jack McGovern  
Coats' Disease Foundation

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# Foundation Leadership

Thirteen Directors Provide Diverse Expertise and Experiences:

- Four Founding Members
- Six Coats' Disease Family Members
- Two Coats' Disease Patients
- Two Researchers
- One Pediatric Retina Specialist Who Chairs the Scientific Advisory Board

## **Board of Directors**

*Negar Souza - Chair*

*Jack McGovern - Vice Chair*

*Joe Vollert - Immediate Past Chair*

*Ed McGovern - Co-Founder*

*Tina McGovern - Co-Founder*

*Russell H. Miller, J.D., Ph.D. - Secretary & General Counsel*

*Joseph Galligan, CPA - Treasurer*

*John Bruno - Sgt. At Arms*

*Mary Elizabeth Hartnett, MD - SAB Chair & Board Liaison*

*Gary Brickley*

*Jack McGovern*

*Lisa Richardson*

*Carol Rossi*

*Alison Comer*

## **Scientific Advisory Board**

*Mary Elizabeth Hartnett, MD - Director of Pediatric Retina, University of Utah*

*Michael Jumper, MD - West Coast Retina*

*Thomas Lee, MD - Director of The Vision Center at Children's Hospital Los Angeles*

*Franco Recchia, MD - Tennessee Retina*

*Lejla Vajzovic, MD - Assistant Professor, Duke University Dept. of Ophthalmology*

*Sherri Van Everen, PharmD - VP of Ophthalmology Clinical Development, REGENXBIO, Inc.*

## **Foundation Staff**

*Deborah J Marron, Ed.D.  
Executive Director*

*Sarah Kopac  
Community Engagement Manager*



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# Coats' Disease Facts

Coats' Disease is a rare disorder characterized by abnormal development of the blood vessels in the retina. The retina is tissue lining the back of the eye that transmits light images to the brain and allows a person to see. In Coats' Disease, the blood-rich retinal capillaries leak fluid into the back of the eye. The leakage causes the retina to swell and may lead to partial or complete retinal detachment which can cause vision loss or the loss of an eye.

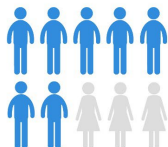
Coats' Disease is almost always unilateral (impacting only one eye); in rare instances, both eyes may be affected but the symptoms are typically more severe in one eye. Coats' Disease was described in 1908 by Dr. George Coats. The specific cause of Coats' Disease is not known. It is not hereditary, and no genetic marker has been identified yet. **There is currently no cure.** In the U.S., a rare disease is any disease or disorder affecting fewer than 200,000 people in the United States.

Coats' Disease primarily afflicts children; two-thirds of patients are diagnosed before the age of 17. The average age at diagnosis is 8-16 years, although the disease has been diagnosed in patients as young as four months. Approximately one-third of patients are 30 years or older before symptoms begin. Coats' Disease is seen predominately in males (75%).



## 1908

The year when **Dr. George Coats** described a specific form of exudative retinitis which affected one eye only - we still don't know what causes it.



## 75%

Estimated percentage of **Coats' Disease** patients who are male

## 95%

Estimated percentage of **Coats' Disease** cases that are unilateral



## 11

Average age at diagnosis.



## 1

Number of **501 (c) 3 nonprofits** dedicated solely to finding better treatments and a cure for **Coats' Disease**

## < 200,000

 COATS' DISEASE IS A RARE DISEASE.

In the **U.S.**, a rare disease is a disease that affects fewer than **200,000 people**



In the **E.U.**, a rare disease is a disease that affects fewer than **1 / 2,000 people**



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# Our Impact

Since 2006, we have been laser-focused on the mission and goals we established for the Jack McGovern Coats' Disease Foundation. Some of our recent successes include:

- Offering Research grants specific to Coats' Disease and other retinal diseases which may lead to a cure or improve treatments and understanding of the pathophysiology for Coats' Disease. We support clinical and basic research.
- Partnering with the University of Minnesota Twin Cities and Duke University to expand research to focus on a potentially pathologic signaling pathway involved in a related condition, FEVR [familial exudative vitreoretinopathy], and similar in interest to previous research projects with Genentech and using optical coherence tomography imaging in Coats' Disease.
- Patient Registry, an international patient database for researchers to access. We now have data for patients from nearly 40 countries in the patient registry!
- Awarding Education Grants for junior Fellows to attend important conferences including the American Academy of Ophthalmology, Advances in Pediatric Retina, ARVO, Retina Society, Macula Society so they can learn more about cutting-edge research and treatments for Coats' Disease. By supporting these researchers, we are creating a cadre of motivated scientists who are now focusing on Coats' Disease.
- Establishing a team of parents and patients across the country who are raising awareness and funds in their communities and supporting other newly diagnosed patients and their families. At their suggestion, we now send information packets to new patients and parents and created a private contact directory for parents and patients to connect with each other directly.
- Continuing to expand patient resources such as the Doctor Directory which now contains over 100 doctors from 14 countries. It is the only resource that is dedicated to helping patients and their families locate qualified retina specialists around the world who treat Coats' Disease.

*For a more complete list of our accomplishments, please visit:*

<https://coatsdiseasefoundation.org/research/our-impact/>



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# The Faces of Coats' Disease



## Mason

This is our bright, bubbly, energetic, funny, joyful, and handsome son, Mason. When he was four weeks old, we started to recognize something seemed a bit off. He was not meeting developmental benchmarks appropriate for his age and did not respond to us the way one would think a new baby would respond to their parents. After undergoing hearing and vision tests, we were able to rule out hearing loss, but not vision.

Mason's ophthalmologist was confident he had a disease called Persistent Fetal Vasculature. She discussed the need for contact lens, glasses, and patch therapy after surgery. She also mentioned he may need multiple eye surgeries. She told us that there would be limitations on the things he would be able to do and participate in growing up. We were told things like "sports could be a challenge," "he can never be a pilot," and "he can never be a surgeon." Immediately, our world came crashing down on us. One minute, I was holding my sweet baby boy, thinking he had the world at his fingertips. Then "BAM," life as we knew it and dreamed

it would be over! I cried and was sick to my stomach for months.

After our initial appointment, we received a call that surgery had been scheduled for December 14, barely a week before our first Christmas with Mason. It was to be a co-surgery with one of two Retina Specialists who work with children in the state of Colorado. Upon Dr. Mathias's review of the ophthalmologist's notes and photographs of Mason's eye, it was decided the required procedure was much too complex and it would be better for the Retina Specialist to perform the procedure alone. In other words, the damage to Mason's eye was far worse than originally thought.

On December 14, 2018, at just four months old, Mason underwent his first of many surgeries. While Dr. Mathias was operating, he discovered Mason had a completely different disease than the original diagnosis and our sweet baby was diagnosed with Coats' Disease. Thus began our journey of research, discovery, collaboration, and the fight to help our son.

The most terrifying part of all this was the sense of isolation we felt. There is very little information about the disease online, very few doctors in our region have knowledge, and there is only ONE non-profit that exists to help raise money and awareness for Coats' Disease. I turned to Facebook to find a community of roughly 600 people to turn to for support. Six hundred, is that it? I thought to myself, this has to change!

Mason has had surgery almost every month since he was diagnosed. He is currently at Stage 3A and his doctor is doing everything he possibly can to keep the disease from progressing further. Mason works with a Physical Therapist, Occupational Therapist, and Vision Teacher to help with his fine motor skills and getting him caught up to his peers. If you were to meet Mason, you would never know he is blind in one eye. He does not let his limitations slow him down. He enjoys music, figuring out how things work, climbing, swimming, his dogs, and reading. Mason is the toughest, bravest, strongest, most positive person we know. He is a true inspiration to us and we wake up every day with the goal to be better parents than we were the day before. We are in this fight together with you, our family, and friends. Together we will find a cure.

For more stories of Coats' Disease patients, please visit our website at

<https://coatsdiseasefoundation.org/testimonials/>



## Jessie

So, after 16 years of being diagnosed with an eye condition, I've finally decided to share my story.

I was very ill at just two-years-old and wanted to sleep constantly. I was taken to London Hospital where I was told I had Coats' Disease after many tests and finding out my eye pressure was extremely high. Since then, I've had an operation on my eye, as well as constant trips to Brighton Hospital and Conquest. I started wearing a cosmetic contact lens to cover the eye at just age eight because of the comments I got on the appearance of my eye. I remember feeling very insecure about myself and wondering why I didn't look like everybody else. Being worried about what people think about you isn't what someone should be thinking at just 8-years-old!

I can't say life has been easy living with something like this, with constant eye infections and excruciating pain, as well as being anxious and depressed from a young age because of it. But, I just remember that people go through much worse.

Today, at 18-years-old, I have just learned that I am who I am. I once got asked a question, "if you could change something about yourself what would it be?" And I always used to reply "I'd change my eye, I hate it." But I thought long and hard and realized, "You know what? It is who I am. Without it, I wouldn't be the girl I am today. If it's taught me anything it's to appreciate what you have in life."

Coats' Disease isn't made aware of enough and by sharing my story I really hope to help other people out there suffering with the same thing. It isn't easy, but it definitely makes you a stronger person!



## Andreas

About six years ago, I had taken my son, Andreas (age four at the time), to the eye doctor because I thought he had poor vision. Around that time, he was just beginning to read, and I noticed he would get close as he was attempting to read, so I thought he would just need glasses. Upon his eye exam, the doctor noticed a lot of scarring in his left eye. After asking me if he had ever experienced trauma or an infection to his eye, he referred me to a Children's Hospital for further assessment. Based on the doctor's report, we were seen the following day. Things happened really fast!

After performing test after test, and ruling out other possibilities, it was determined that Andreas had Coats' Disease. I'd never heard of it before that point. It was determined that he was at 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, Andreas had nine surgeries to his eye. His retina had detached, so the surgeries were

really just to try to reattach and to stop any leaking that would have caused him a great deal of pain. 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.

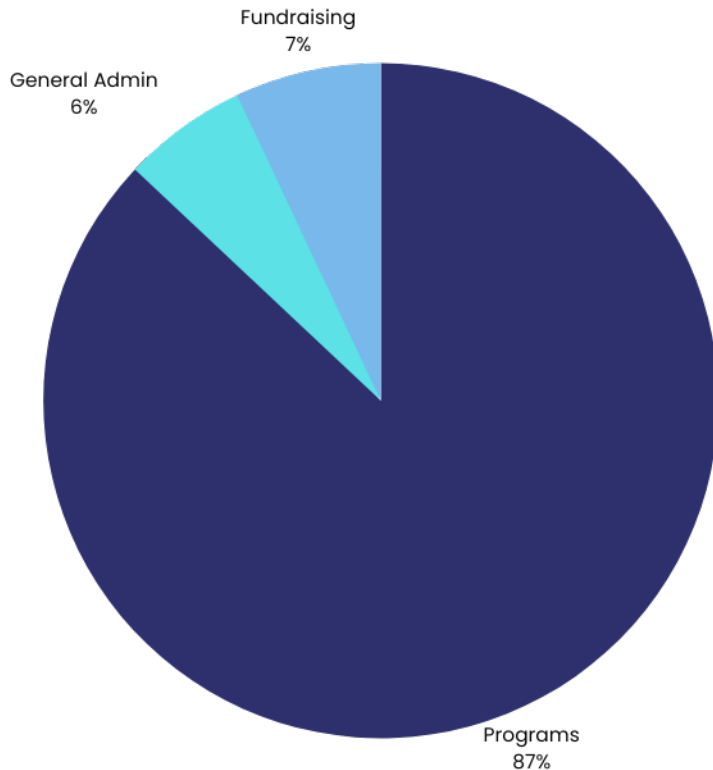
We are currently five years post his last surgery and just had our final appointment with his surgeon. Things are looking as great as they will be, considering the stage we were when he was diagnosed. He will remain legally blind in that eye due to the scarring but will lead a normal life. He was most excited to hear that he can continue to play his favorite sport, baseball! He'll always have to wear glasses even though he doesn't need them to see. His right eye has perfect vision and his left eye can't be corrected with glasses. He still doesn't quite understand that the glasses are for protection, so it is always a battle with him to wear them all the time!

I can say that the road was very rough! It doesn't get easier seeing your child getting put to sleep, no matter how many times you've been through it. It didn't get easier for him either. Each visit was filled with so many eye drops, and most of the time, it took an army to hold him down. By the way, he still hates eye drops. My hope is that a cure is found. I hope that families beginning this journey find a network of people to support and encourage them. It can be overwhelming, but I promise, at some point, there is the light at the end of the tunnel!

# Financial Responsibility

The Jack McGovern Coats' Disease Foundation is the LEADER in advancing research into Coats' Disease. We are an organization with lean operating costs, so contributions make a direct impact.

In 2022, 94 cents out of every dollar spent went directly to support our mission and goals - raising awareness, funding research, and building patient resources.



## **NON-PROFIT STATUS**

The Foundation is a Non-Profit Corporation and a recognized IRS 501(c)(3) charitable organization. All donations are tax deductible. Our EIN is 26-2439083.

*We pride ourselves on transparency. To access our most recent tax returns, please visit: <https://coatsdiseasefoundation.org/about-us/>*



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# Contact Us

## WEBSITE

[www.coatsdiseasefoundation.org](http://www.coatsdiseasefoundation.org)

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## Executive Director

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## LEGAL INQUIRIES

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## FINANCIAL INQUIRIES/DONATIONS

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San Mateo, CA 94401

# Resource Links

**Doctor Directory:** <https://coatsdiseasefoundation.org/coats-disease/find-a-doctor/>

**Patient Registry:** <https://coatsdiseasefoundation.org/research/patient-registry/>

**Patient & Family Contact Directory:**

<https://coatsdiseasefoundation.org/patientandfamilycontactdirectory/>

**Mailing List Sign Up:** <https://coatsdiseasefoundation.org/newsletter/>

**Become a Foundation Sponsor:** <https://coatsdiseasefoundation.org/donate/>



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