Jack McGovern
Coats' Disease Foundation

ANNUAL REPORT

2023

Jack McGovern Coats' Disease Foundation

FIGHTING TO FIND A CURE FOR COATS' DISEASE

2023 ANNUAL REPORT

The Work Continues...

Dear Friend,

I am pleased to share with you our annual report. I can't thank you enough for all of your support and generosity to the Jack McGovern Coats' Disease Foundation in 2023!

Your continued support has enabled us to build on our research efforts, increase awareness, support more community events and provide more valuable resources for patients and their families.

With your partnership, some of our achievements in 2023 include:

- Sponsoring presentations and panel discussions on Coats' Disease during the Advances in Pediatric Retina Conference that further promoted research and raised awareness of the Jack McGovern Coats' Disease Foundation's impact as a major force in the battle against Coats' Disease.

- Funding three new research projects that have the potential to impact the diagnosis and treatments of Coats' Disease;

- Funding Education Grants for early-career retina specialists to learn more about cutting-edge research and treatments for Coats' Disease, thus creating a cadre of motivated scientists who focus on Coats' Disease.

As a mother of a 14-year-old son who has Coats' Disease, I am excited about the Foundation's initiatives that are focused on education, awareness, early detection and long-lasting support both emotionally and medically. It is my goal that for patients like those whose stories we share in this report, diagnoses and treatments for Coats' Disease will be improved and we work towards finding a cure.

The Jack McGovern Coats' Disease Foundation is the only Patient Advocacy organization that is focused solely on Coats' Disease. My dream is to ensure that 10 years from now, the Foundation is still here thriving, supporting, listening, and leading the way to a cure for Coats' patients and that I am reading an annual report sharing the accomplishments over the last decade!

With your help, we will ensure that these dreams become a reality. On behalf of the Board of Directors and all who are impacted by this disease - THANK YOU!

Sincerely,

Negar Souza, Chair
Board of Directors, Jack McGovern Coats' Disease Foundation

OUR STORY

The Jack McGovern Coats' Disease Foundation is a 501(c)(3) non-profit charitable Foundation that was established in 2006 by the parents of Jack McGovern as a promise to their son that they would never rest until there was a cure for Coats' Disease.

At the age of ten, Jack McGovern discovered that he could no longer see the big E on the eye chart. Jack was seen by knowledgeable retina specialists and was diagnosed with Coats' Disease, a rare disease that can cause blindness.

For Jack, treatments for this rare eye disorder included four surgeries on his eye. The surgeries stopped the blood vessels from leaking but left Jack with a blind spot in the center of his left eye's visual field. Jack is now an adult who, despite his vision loss, has a bright future. As with all Coats' Disease patients, Jack will need to monitor the progression of his disease for his entire lifetime.

To help Jack and other Coats' children and their families, the Jack McGovern Coats' Disease Foundation was formed to raise awareness of Coats' Disease and to raise funds to encourage and support research to find a cure for Coats' Disease.

Today, we have become the preeminent source for information and resources to help educate and support families in their fight against Coats' Disease. We are the only organization that is totally focused on finding a cure for Coats' Disease.

OUR MISSION

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.

OUR VISION

Our Vision is to find a cure for Coats' Disease.

OUR GOALS

Our Goals are to:

- Fund Research
- Raise Awareness
- Expand Patient Resources

Jack McGovern

Coats' Disease Foundation

LEADERSHIP

We are deeply grateful to the Jack McGovern Coats' Disease Foundation Board of Directors and Scientific Advisory Board members, who volunteer their time and expertise to advance the mission of the Foundation.

Foundation Board Members and Scientific Advisory Board Members gathered at the 2023 APR Conference.

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Tina McGovern, Founder & Past Chair, Parent
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Lisa Richardson, Parent
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deborahmarron@curecoats.org

Sarah Kopac
Community Engagement Manager
skopac@curecoats.org

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Assistant Professor, Duke University Department of Ophthalmology

Sherri Van Everen, PharmD
Vice President, REGENXBIO

WHAT IS COATS' DISEASE?

Coats' Disease is a rare disorder characterized by abnormal development of the blood vessels in the retina. The blood-rich retinal capillaries break open, leaking the serum portion of the blood into the back of the eye. The leakage may lead to partial or complete detachment of the retina.

If caught early, some level of vision can typically be restored. If not treated until its later stages, complete loss of vision can occur. In the final stage, enucleation (removal of the affected eye) may be necessary. Coats' Disease is almost always unilateral (affecting only one eye).

Symptoms may include the eye turning outward or inward (strabismus), a yellow or white reflection (leukocoria), which often shows in flash photography, signs of loss of depth perception and parallax, and deterioration of eyesight.

Treatment varies by patient and may include laser therapy, cryotherapy, injections, and surgery.

There is no known cause and currently no cure.

WHO IS AFFECTED?

About two-thirds of Coats' patients are diagnosed as children under age 17. The average age at diagnosis is 8–16 years, although the disease has been diagnosed in patients as young as 2 months. The peak age of onset is between 6-8 years of age. Approximately one-third of patients are 30 years or older before symptoms begin.

It is estimated that 75% of Coats' patients are male.

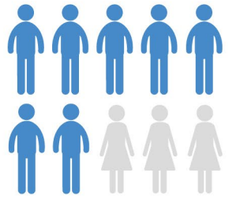
Coats' Disease does not appear to be inherited and has no reported racial or ethnic predilection.

Jack McGovern
Coats' Disease Foundation

COATS' DISEASE FACTS

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.

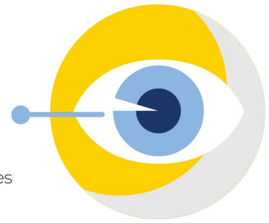


75%

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**

Scan for more information or visit curecoats.org

OUR ACHIEVEMENTS

The Jack McGovern Coats' Disease Foundation works tirelessly year-round to serve the Coats' community and to forward our mission of raising awareness, building patient resources, and finding a cure for Coats' Disease.

The 2023 Golf Outing welcomed the most Coats' patients we've ever had in attendance!

Advanced towards the second phase of our research partnership with Genentech which is exploring a genetic connection to Coats' Disease.

Continued our partnership with the Macula Society to offer and promote research grant funding among retina specialists to spur more research on Coats' Disease.

C.A.N. Coats' Ambassador Network

Expanded the CAN - a team of patients & families raising awareness and funds in their communities - connecting with newly diagnosed patients and conducting outreach to health care providers & vision screeners about the symptoms of Coats' to promote earlier diagnosis and prevent vision loss.

Promoted the Patient Registry, an anonymous collection of data from Coats' Disease patients available to researchers. In 2023, we increased the number of registered patients to nearly 500.

Increased the Patient & Family Contact Directory to include more than 200 families in 39 countries. The Directory provides a way for Coats' patients and their families to connect with others directly.

Awarded Research Grant funding to support three new research projects on Coats' Disease demonstrating that our efforts to raise awareness of our Research Grant program among Retina Specialists are having an impact.

Sponsored three Education Grants for early career doctors to attend key retina conferences, where they learn more about Coats' Disease and are encouraged to focus their research on Coats'.

Advances in Pediatric Retina APR 2023

Sponsored sessions on Coats' and raised awareness of Coats' and the Foundation during the 2023 Advances in Pediatric Retina (APR) Course, attended by more than 200 pediatric retina specialists from around the world.

Hosted the 17th Annual Golf Tournament, where we welcomed long-term and new supporters for our biggest fundraiser of the year.

Raised awareness and expanded the Coats' Community through the 2023 Cure Coats' in-person 5K in Brisbane, CA and the virtual 5k "run/walk/whatever to get to 5k" events which took place around the world.

Expanded and maintained patient resources, including a Patient & Expert Video Library, an updated brochure, and informational materials such as "the Symptoms of Coats' Disease" to facilitate earlier diagnosis of Coats' Disease.

Created "Connecting for a Cure" to encourage and support Coats' "Crusaders" everywhere to host awareness- and fund-raising events in their communities. Two notable events included Sip, Shop, & Support in San Francisco, CA & Notes for Coats' in Nashville, TN.

Updated and redesigned our website for ease of navigation so that visitors can quickly find the information and resources that they need.

STORIES OF YOU

For so many families, reading about the experiences of others with Coats' Disease is comforting, reassuring, and a necessary part of managing their own Coats' journeys. So many Coats' patients have overcome challenges to reach their full potential, inspiring others along the way.

These stories are an important reminder that all Coats' patients live with Coats' Disease for a lifetime. Many go on to lead "normal" lives and achieve great things; however, they must closely monitor their eye health for the rest of their lives.

We are so thankful to those who have opened up and shared their own Coats' journey with us and the world. Because of you, we are inspired every day to keep spreading awareness and fighting for a cure for Coats' Disease.

Marcello

In November 2021, we noticed our son Marcello's left eye drift to the side. We reached out to our pediatrician to schedule an exam. During this time, covid omicron had spread to its highest point, and we couldn't get an appointment until January 2022. We didn't think think that the wait would make a difference. My husband had amblyopia when he was a kid and he had to wear an eye patch and then eventually wear glasses. We assumed Marcello had the same condition. However, after a referral to the Pediatric Optometrist and a 45-minute exam, Dr. Buu found some yellow spots in the back of Marcello's left eye. She recommended another referral but this time to an Ophthalmologist and the Vitreo-Retina team. She asked if I could stay and wait for the Ophthalmologist, Dr. Kevin Merrill, to arrive or return another day. I decided to stay, and I'm so glad I did because time was of the essence. After Dr. Merrill examined Marcello's eye, he suspected the yellow spots and the cause of drift were due to Coats' Disease.

Dr. Merrill explained Coats' Disease to me, a rare disorder characterized by abnormal development of blood vessels in the retina. Therefore, Marcello could experience loss of vision in that left eye due to the changes in the retina and, depending on the progression of the disease, retinal detachment. After hearing the news, I immediately froze. I couldn't understand what he told me, my little boy with a rare eye disease and no cure! My son could go blind in his left eye?! I had to ask Dr. Merrill to repeat the information to me. Since Marcello was only 20 months old then, he wouldn't cooperate for a complete exam unless he was asleep. We quickly scheduled surgery for the following week, where Dr. Merrill and Dr. Lewis could examine Marcello's eye, confirm it was Coats' Disease, and start immediate laser treatment.

A year later, after four laser treatments, and a continuous eye patch for a few hours a day, Marcello's vision in his left eye went from 25% to 98%. It was the best news we had received. Marcello continues to wear an eye patch for a few hours daily; we aim for 20-25 hours per week. We continue to monitor his vision and attend 3-4 monthly check-up appointments. While currently, there's no cure for Coats' Disease; we continue to have faith that he won't need any further laser procedures.

Throughout this journey, I struggled to find a bilingual book that empowered Marcello to wear an eye patch, so I did what mothers do best, I created my own. El Pirata y su Parche Magico/The Pirate and his Magical Eye Patch was published this past fall.

As parents, our journey with Coats' Disease has been overwhelming, scary, and emotional. However, we are incredibly thankful for the care and support from Dr. Buu, Dr. Merrill, and Dr. Lewis from Kaiser Permanente as well as a huge thank you to the Jack McGovern's Coats Disease Foundation, who have provided us with many resources and connected us with other Coats' families.

Jack

For a couple months, Mike and I had been noticing that Jack's right eye was lazy at times. When I took Jack and one of his sisters to the pediatrician for a physical at the beginning of June 2015, the pediatrician didn't see anything wrong with Jack's eye. But he asked me to keep a journal of when we noticed it being lazy and then we would check the eye again in a month. At the same appointment, my daughter failed her eye exam. So I decided to take Jack, with his sister, to the eye doctor, just to make sure everything was ok.

A week later, I left the optometrist thinking Jack had cancer.

At the appointment, the optometrist could see swelling around Jack's optic nerve and problems around his retina. She said he needed to be seen right away by an ophthalmologist and made an appointment for Jack the next day. She also asked me if I ever noticed a glow in Jack's eye in pictures. That night I went home and looked through our pictures and found several where Jack's right eye showed the glow. I didn't know this was an indication that something was wrong.

We saw Dr. Kipp the next morning and, after looking at Jack's eye, he thought it might be Coats' Disease and referred us to Dr. Shapiro, a retinal specialist. At this appointment, we also found out that Jack had very little vision in his right eye. We were shocked because you would never know that Jack only had vision in one eye. A week later, we saw Dr. Shapiro, who also thought it was Coats' Disease, but needed to do an exam under anesthesia (EUA) to confirm. Jack had his first surgery on June 30, 2015.

About an hour into surgery, Dr. Shapiro called us to confirm that indeed Jack had Coats' Disease and he did laser on his right eye. The first laser treatment went really well. Jack is closely monitored by both Dr. Shapiro and Dr. Kipp. Since Jack has very little vision in his Coats' eye (no central vision), he wears protective eye wear to protect his non-Coats' eye. Jack had a second laser surgery on November 29, 2016 and a third laser surgery on October 17, 2017 to stop current leaking. He continues to be monitored closely.

One would never know Jack had Coats' Disease. He is a happy, active 10 year old who loves to play basketball, baseball, swim, and play with his three siblings. Coats' doesn't slow Jack down!

Maddie

"My superpower is I can do things with one eye that most people need two for!"-Mighty Maddie

Maddie was diagnosed with Coats' Disease right after her third birthday at the University of Chicago hospital. Two weeks prior to that, she was having a routine eye exam in Kansas City where they quickly realized something was VERY wrong with her left eye (we thought she had a lazy eye). Fast forward to a cancer MRI, two exams under anesthesia, and her first flight...we finally got our diagnosis: Coats' Disease.

Maddie has had 11 surgeries in three years. It is still unknown how much blindness she has in her left eye, but we are hopeful she will not be 100% blind. Time will tell and our number one priority is to stop the bleeding/leaking of fluid in her eye so that we can eventually see the damage to her retina.

Mighty Maddie is a WARRIOR. She is incredibly resilient, strong, smart, and has a BIG personality! Maddie understands she is unique and doesn't let that slow her down. She has found her voice and educates people she meets about Coats' Disease.

There will be struggles but we will continue to encourage her to push past her fears when things are hard with partial blindness. She continues to amaze us and we know God has big plans for her! We pray that a cure can soon be found.

Mailo

My son, Mailo, was diagnosed with Coats' Disease a few weeks before his fifth birthday during a routine eye exam. He's been wearing glasses since the age of three for minor shortsightedness, which runs in the family. The affected blood vessels are not near his main optic nerve so he never had any symptoms – meaning this was a surprise find. Our optometrist said he was the youngest patient he'd ever come across with this kind of disease and that we were lucky he was diagnosed so early before he presented any symptoms, at which point the damage is often irreversible.

After his diagnosis, we were immediately passed onto an eye surgeon for further tests, including Ophthalmic Fluorescein Angiography. It was hard trying to explain the problem and the procedures to Mailo since he was still so young but he was been a real trooper about it all and still manages to greet the doctors and nurses with a big smile on his face.

We've been told that he will need eye laser surgery in the not too distant future to slow down the disease but since he's still so young they have advised against it for now because the risks of putting him under general anesthetic currently outweigh the benefits.

We're grateful to our Optometrist, Dr Amrik Panesar for finding the disease and acting so quickly to get him properly checked out.

Lucy

I'm a 23-year-old female living with Coats' Disease in my left eye. I have total vision loss in that eye, but to look at me now you would never think that there is anything wrong with my eye! I've had Coats' Disease for as long as I can remember and, as a result, I've been in and out of hospitals for most of my childhood. It's been a struggle throughout my childhood living with Coats' Disease. It's been very challenging. For me, going blind in my eye is something I've always lived with and, therefore, really don't know anything different, but I've always wondered what it would be like to be able to see out of my left eye.

I know my disease is something that makes me the person I am today, but I still find being confident a challenge, as I now have a white pupil. I spend my time trying to hide myself away from it and even have a contact lens to hide my pupil. To be honest, it does a good job. I've also had squint surgery a couple of years ago to straighten my eye and give me some of my confidence back.

From time to time I think, "Why me? Why do I have to live with this for the rest of my life?" And there's nothing really I can do to change it. But it's been a part of me for most of my life now. I still find it hard from time to time to be myself because I think everyone can tell there's something wrong with me so I've spent most of my life hiding away and trying to cover my eye up.

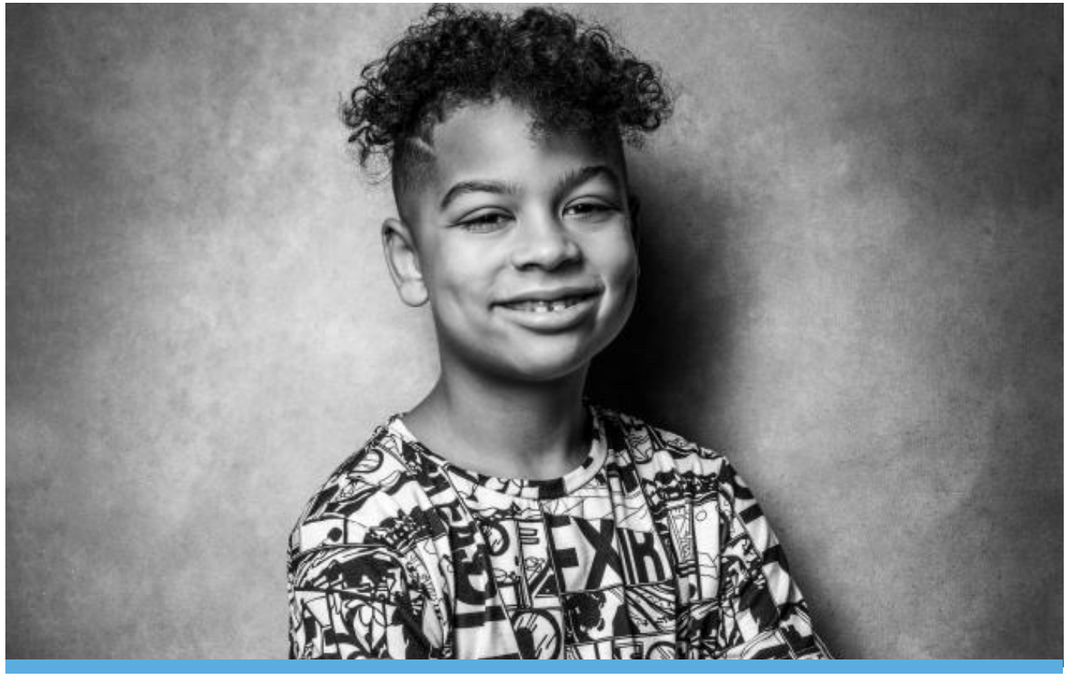
I've never shared my story about having Coats' Disease but knowing many other people live with this has made me want to share my story.

Albi

It was sometime in the last quarter of 2022 when we noticed that Albi had a lazy left eye. He was only 2 years old at the time. After so many eye tests, laboratory tests, an eye ultrasound, and an MRI, retinoblastoma was ruled out and Albi was diagnosed with Coats' Disease. I never heard of that disease and neither had any of our family members. I did several searches and that's how I got to know of the Jack McGovern Coats' Disease Foundation.

Fast forward to today, Albi has undergone cryotherapy (he was under general anesthesia) to freeze the leaking blood vessels and prevent retinal detachment. Albi is such a playful kid and he never lets Coats' affect his happy days. His doctors see him monthly to check the decrease of the fluid in the affected eye and to monitor his good eye. He is also due for Avastin injections monthly.

We are praying and hoping that a cure will finally be developed.



Ethan

My sweet little boy came inside one summer day in 2020 saying something got into his "good eye." This little remark was the curve ball that ultimately led to a surgery and countless appointments over the last few years.

The path to diagnosis was scary, with Ethan describing the "black dot" in his vision, failing eye tests with the optometrist, and watching the doctors exchange glances as they said they see a "mass" and writing an immediate referral to Texas Retina. The problem was that only a few doctors will see children, but we were scheduled with Dr. Ashkan Abbey the next day. After what is now our new normal of poking and prodding, scans, drops, a dye injection, and pictures, he was diagnosed with Coats' Disease and surgery was scheduled.

I went home relieved and equally concerned. We spent several weeks trying to find as much information as possible.

Recently, we had a positive visit at Texas Retina Associates of Dallas this October and get to keep our "every 6 months" checkup appointment compared to the every 3 weeks he was on that first year. After the initial surgery, he had 2 additional injections to dissolve the leaking fluid, and has been in stable condition for a year, officially.

In all honesty, I think this disease is harder on me, the lack of answers, the guilt, the research, the unknown. He simply enjoys the promise of Chick-fil-A after every doctor visit.

Luckily, this has not slowed him down but it is something we will manage and monitor as best we can. This is just part of our journey now and Ethan is a happy 5th grader, enjoying his giant puppy, playing piano, and playing video games

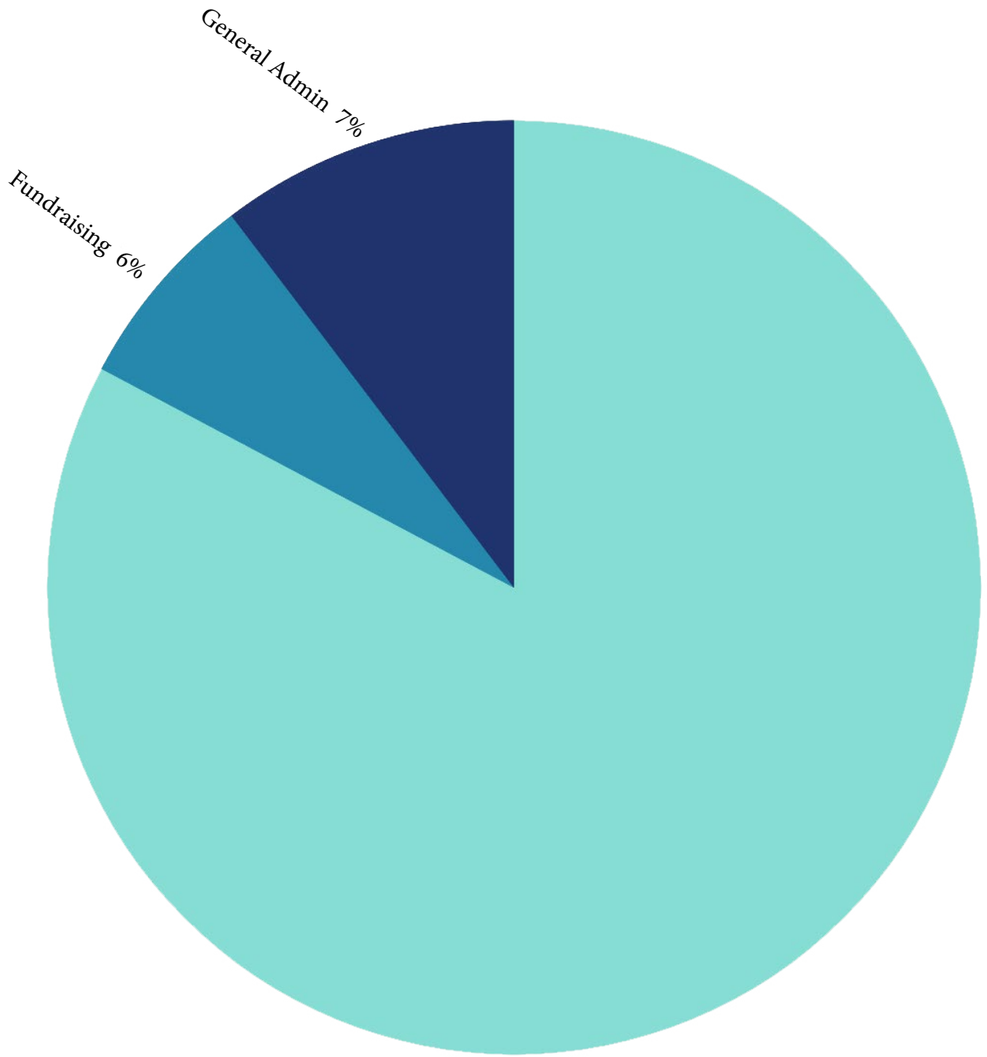
I appreciate organizations like the Jack McGovern Coats' Disease Foundation to provide information, an outlet, and a voice.

FINANCIALS

Fiscal Year 2023 Expenses (January 1, 2023 – December 31, 2023)

We are proud to report a year of strong support from our amazing donors who have enabled us to continue raising awareness, building patient resources, and funding research for a cure! As we look ahead to 2024, we remain committed to fiscal prudence and responsibility so that we can continue to serve the Coats' community and the programs that enable researchers to advance their important work.

Foundation Board Members with 2023 Education Grant & Research Grant Recipients



Out of every dollar spent, 91 cents goes directly to support the mission and goals – raising awareness, funding research, and building patient resources.

Programs = 87% of total expenses

Fundraising = 6% of total expenses

General Administrative = 7% of total expenses

THANK YOU!!

2023 SUPPORTERS

Your support is so important to us and we are grateful to have your help in finding a cure for Coats' Disease!

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All About Parking, Inc.
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Tim Kovac
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Donna Lagasse
Brett Lanham
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Christy Rhoades
Keith and Lisa Richardson
Bradford Riley
Rincon Family Charitable Fund
Christopher Rogers
John Rollo
Lance Romero
Kevin Rooney
Alex Rosko
Tom Rosman
Craig and Carol Rossi
Michael Rouan
Nick Rougely
Michael Sackley
Isabelle Salesse
Dennis Saucerman
Jane Schapker
Samuel Scull
John Selway
Michele Sevilla
Joanna Sharp
Joe Shasky
Patty Shimek
Diane Siljevinac
Lauren Simpson
Paul Simpson
Singer Associates Inc.
Steve Sirianni
Skyline Construction
Kate Smalkin
Claudia Smith
Hannah Smith
Kyle Smith
Michael Smith
Jalane Sommers
Riley & Jack Soto
Steven Souza
Darius Souza
Negar Souza
Suzie Souza
St Ignatius College Prep
Steel Fab Inc
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Tennessee Retina
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Workday
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Jodie Yazvec
Grace Yi
Dan Yongue
Rebecca Young
Zareen
Alex Zera
Zerga Insurance Services
Zscaler

JOIN THE FIGHT!

Coats' patient, Duncan, and his classmates from Hunterville School in New Zealand celebrating their participation in the 2023 Cure Coats' 5K!

Together, we can do so much!
Let's continue to build awareness and fight for a cure for Coats' Disease!

Visit Us online at www.coatsdiseasefoundation.org. Our website is full of resources for patients and families and serves as the central hub of our Foundation.

Volunteer. We are always looking for volunteers for our events, committees, and community development. To learn more about volunteer opportunities, email us at contact@curecoats.org.

Sign up for our monthly newsletter to stay in the loop with the latest happenings at the Foundation. Register online at www.coatsdiseasefoundation.org.

Participate in events. We hold two major fundraising events each year - the Golf Tournament and the Cure Coats' 5K (in-person and virtual). In 2023, we also launched the global Connecting for a Cure events. These are great ways to support the Foundation in a fun, family-focused way, wherever you live around the world!

Like Us on Facebook and follow us on Twitter and Instagram (@curecoats), and LinkedIn to stay up-to-date with the latest news, photos, and events.

These are the Faces of Coats' Disease.

Jack McGovern
Coats' Disease Foundation

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