



Jack McGovern
Coats' Disease Foundation

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Web: coatsdiseasefoundation.org

Dear Coats' Patients and Parents,

On behalf of Jack McGovern, his parents, and the other patients and families in the Coats' community, I would like to thank you for reaching out to us. As one Coats' parent advised, "We have now joined a club that we did not ask to join. Let's make it the most positive experience it can be." With that in mind, we are sending you this "welcome packet" of information, resources, and other materials to support you and encourage you to connect with our community.

The Foundation was established in 2006 by Ed and Tina McGovern as a promise to their son, Jack, that they would never rest until a cure for Coats' Disease was found. Our mission is: To raise funds to support research, raise awareness, expand patient resources, and offer all Coats' patients hope and improvements as they wage a lifelong battle against Coats' Disease and blindness.

Please sign up for our mailing list by visiting our website at www.curecoats.org where you will find resources and information about this disease. We encourage you to add your anonymized information to the Coats' Disease Patient Registry which compiles data accessible to researchers who are working to cure Coats'; the link is located under the *Research* tab. If you wish to obtain a second opinion, you may access the Doctor Directory under the *Coats' Disease* tab to identify a qualified retinal specialist who has experience in treating Coats' Disease.

We understand that speaking with other Coats' parents and patients can be very helpful as you navigate through diagnosis and treatments. If you would like to connect with other Coats' families, especially someone in your area, you can sign up for inclusion in our online private Patient and Family Contact Directory located under the *Contact* tab on our website.

We are here to assist you! Please contact me if there is anything we can do. We wish all the best to you and your family as you make your way on this journey.

Sincerely,

A handwritten signature in cursive script that reads "Deborah J. Marron".

Deborah J. Marron, Ed.D.

Executive Director

deborahmarron@curecoats.org

COATS' DISEASE

INFORMATION SHEET

FOR PATIENTS
& FAMILIES

WHAT IS COATS' DISEASE?

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. 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%).

SYMPTOMS

Every patient is different; some may not exhibit any obvious signs and the patient may not always notice a change in vision in one eye if the other eye compensates for it. Experts agree that children who exhibit the following early warning signs should seek an evaluation immediately from an optometrist or ophthalmologist:

- **Eye turning outward or inward** (called strabismus).
- **Yellow eye in flash photography or a yellow reflex from the pupil.** Just as the red-eye effect is caused by a reflection off blood vessels in the back of a normal eye, an eye affected by Coats' will reflect yellow in photographs as light reflects off cholesterol deposits.
- **Signs of loss of depth perception and parallax.** Since depth perception relies on good and equal vision in each eye, a significant loss of vision in one eye will result in loss of depth perception.
- **Deterioration of eyesight in either the central or peripheral vision.**

Over time, Coats' Disease may cause detachment of the retina and substantial loss of vision. Additional signs may appear as Coats' Disease progresses, including elevated pressure inside the eye (glaucoma), clouding of the lens of the eye (cataract), reddish discoloration in the iris due to the growth of new blood vessels in the iris (rubeosis iridis or neovascular glaucoma), shrinking of the affected eyeball (phthisis bulbi), and/or inflammation of eye (uveitis).

PATH TO DIAGNOSIS

Children typically first see their pediatrician, who then refers the patient to an ophthalmologist. They will then refer the patient to a pediatric retina specialist if Coats' is suspected. Adult patients typically see an Ophthalmologist for an initial consultation and should be referred to a retina specialist.

To identify an Ophthalmologist with experience in treating Coats' Disease, visit www.coatsdiseasefoundation.org/coats-disease/find-a-doctor/.

Coats' Disease is divided into 4 stages, from the mildest to most advanced. Because Coats' often presents at a very advanced stage, it can be mistaken for Retinoblastoma, which is an extremely rare malignant tumor or form of cancer that develops in the retina. Retinoblastoma patients are usually diagnosed before the age of three. Common presenting symptoms include the white reflex in the pupil (leukocoria) and strabismus or eye misalignment. The presentation of symptoms in Retinoblastoma can be identical to those in Coats' Disease, therefore it is very important to correctly distinguish Coats' Disease from Retinoblastoma, since untreated Retinoblastoma can be life-threatening. Differentiating Coats' from Retinoblastoma often requires an examination under anesthesia and a computed tomography (CT) scan of the eyes and brain.

TREATMENT

The treatment of Coats' Disease is directed toward the specific signs present in each individual. A procedure that uses laser energy to heat and destroy abnormal blood vessels (photocoagulation) and/or a procedure that uses extreme cold to create a scar around the abnormal blood vessels (cryotherapy) are used singly or in combination to treat Coats' Disease. In conjunction with these procedures, steroids or other medicines such as bevacizumab may be injected into the eye to control inflammation and leaking from blood vessels. Surgery to reattach the retina may also be necessary.

If caught early, some level of vision can typically be restored. If caught in late stages, complete loss of vision can occur. Repair of retina previously damaged by the disease is not possible. In its final stages, enucleation (removal of the affected eye) is a potential outcome.



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QUESTIONS TO ASK YOUR DOCTOR

At the Jack McGovern Coats' Disease Foundation, we are often contacted by anxious parents or patients who are seeking information after receiving a diagnosis of Coats' Disease. The questions below are provided as a resource to assist you as you and your doctor decide the best approach for treatment. These questions do not constitute any form of medical advice or diagnosis. Each patient is unique. An experienced retinal specialist who has examined the patient is the best source of information for diagnosis and treatment. We always recommend getting a second opinion. To identify an Ophthalmologist with experience in treating Coats' Disease, visit our web page at www.coatsdiseasefoundation.org/coats-disease/find-a-doctor/.

BEFORE YOU BEGIN

Ahead of any treatments or procedures, it is important to ask yourself and the doctor the following questions:

- How do you know that this is Coats' Disease?
- Has your doctor treated other patients with Coats' Disease?
- Have you sought a second opinion? If not, please consult our Doctor Directory for knowledgeable doctors in your area. (see link above)

COATS' DISEASE QUESTIONS TO ASK YOUR DOCTOR

1. What Stage of Coats' Disease is he/she in?

- Will his/her vision get worse over time?
- Will the eye have pain?
- Will his/her eye start to turn out? Is muscle corrective surgery an option?
- Are cataracts likely?
- How likely is glaucoma? (due to retinal detachment)
- Is there calcification?
- What is the anticipated disease progression?

2. Is there a thorough vision exam available?

- Where is the vision affected? (central /peripheral/ distance)
- Does he /she have depth perception? (3D visibility)
- What about the non-Coats' eye?
- To what extent is his / her vision affected?
- Will we be able to use this as a baseline to measure progress/decline?

3. If there is a retinal detachment:

- What percent is the retina detached?
- Will it continue to detach?
- How quickly can it detach?
- Can you treat with laser or freezing treatments (also known as cryotherapy)?
- Is reattachment surgery advised?
- What are the risks associated with reattachment surgery? (i.e. further vision loss/re-detachment/success rate?)
- Will you be doing retinal mapping to compare progress with laser/cryotherapy?

4. Is laser/cryotherapy always successful?

- What are the risks with scarring?
- What about alternatives such as Avastin / Lucentis, which can help prevent new blood vessel growth?
- Is there a risk when using these anti-VEGF's to the rest of the body?

5. Is shrinking of the eye something to watch?

- What about pain in the eye – is that something to be anticipated? If so, would that indicate a need for removal of the eye (enucleation)?
- What is the difference between eye pain and an eye ache?

6. In his/her Non-Coats' eye, what will you be looking for?

If this isn't Coats' now, can we be confident it won't be in the future?

7. What are the cutting edge treatments on the horizon?

- Scleral shell to cover cataract or turning eye? Retinal Chip? Orbital eye implants? Stem cells to regenerate retinal tissue?

8. What is his / her IOP (Intraocular Pressure)?

- 12-18=normal, under 9 and over 20 a concern?
- What can affect his IOP?
- How can I tell if his IOP is changing?
- What drops are recommended at that point? (Cosopt/Atropine/Iopidine/Generic)?

9. Do you recommend glasses or protective eyewear to prevent injury to his/her non-Coats' eye?

- Polycarbonate Lens glasses? Tinted glasses?
- How often should he/she wear them?
- Should we restrict any sports or activities? Swimming after an EUA (exam under anesthesia)?

10. School recommendations?

- Educate staff and other kids/PE & recess?
- Where is the best place to sit in the classroom?

11. Are there vitamins specifically for the eye?

- What are the benefits of patching therapy and what the intent of patching? Vision therapy?

12. Should both eyes be dilated at each visit? Why?

- Dilating the pupils – how long does it last?
- Will the yellow glow in pictures go away with treatment?

13. What other doctors / specialists do you work with?

- Could his / her Coats' Disease be a symptom of another disorder? (FSHD, FEVR, Retinoblastoma)
- What resources do you have available for newly diagnosed patients/parents?

14. At what age do you stop doing EUA (exam under anesthesia)?

- What is the purpose of an EUA and what can be done during that time?

SHARING A COATS' DISEASE DIAGNOSIS

_____ has been diagnosed with Coats' Disease.

What is Coats' Disease?

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. 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.

If caught early, some level of vision can typically be restored. If caught in late stages, complete loss of vision can occur. Repair of retina previously damaged by the disease is not possible. In its final stages, enucleation (removal of the affected eye) is a potential outcome.

Who has Coats' Disease?

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%). In the U.S., a rare disease is any disease or disorder affecting fewer than 200,000 people.

Is Coats' Disease Contagious?

No, Coats' Disease is NOT contagious and cannot be transmitted to another individual.

Is there a cure for Coats' Disease?

No. Unfortunately, at this time, there is no cure. There are treatments and therapies to help retain vision and slow progression of the disease; however, there is currently no reversal for lost eyesight.

What does this mean for _____?

_____ can do all of the things that other kids can do. We just have to be very careful and protect the healthy eye, and always be aware of what's happening with the Coats' eye as things can change quickly. Any changes in the Coats' eye, such as pain or sensitivity, need to be taken seriously and addressed immediately. These changes could be a sign or symptom that requires medical attention in order to preserve vision.

Things to know specifically about _____:

- Must always wear glasses
- Must always wear protective eyewear when participating in physical activities
- Other: _____

*Place photo
of patient here*



THE FACES OF COATS' DISEASE

Stories of strength and determination



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.



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!

THE FACES OF COATS' DISEASE

Stories of strength and determination



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!



Brian

I was diagnosed with Coat's Disease when I was 14 years old, very traumatic at that age, but as time passed, I became more accustomed with the situation. I learned to drive at age 17 and six months later passed the driving test and was retained in employment with a local bakery as a driver/salesman. No one realized that I could not see in my left eye. I didn't feel any different to other people once I had naturally adapted to various initial annoyances, (i.e. misjudging simple things, picking up a fork and missing it).

As time went by, a very large cataract developed, the eyeball became bloodshot, and the iris was just like a little silver ball. Gradually, pain developed. On several occasions, the doctor was called during the night and morphine injections were given. This was during my mid-20s. I was prescribed tablets to relieve pressure and a strong tablet for the pain. Pressure behind the eye is hard to describe.

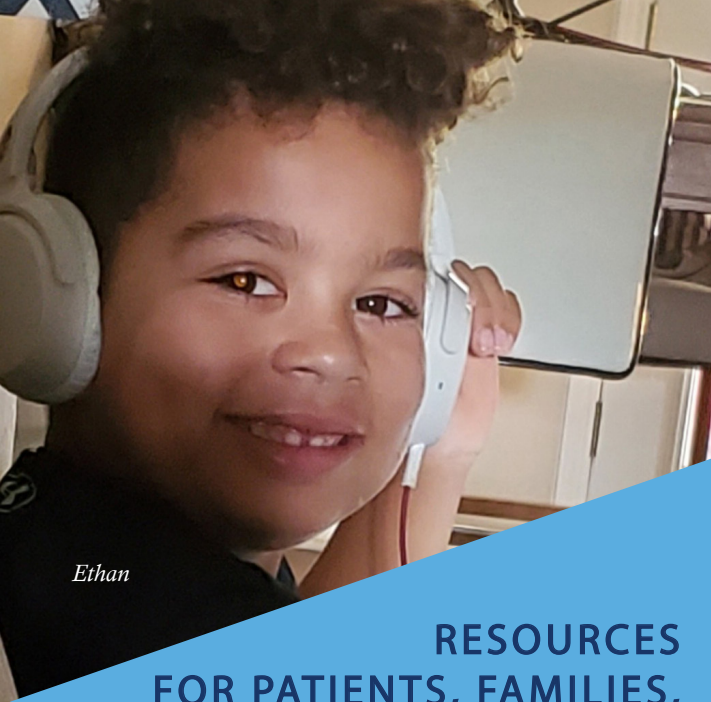
I underwent various tests during the 14 years before I was asked by an ophthalmic surgeon to consider enucleation. He advised that I go away and consider it, for two weeks explaining that the eye was no good, it had died. That was a Monday. I explained that there was no need to consider. I was admitted to hospital on the Wednesday, operation Thursday, resting Friday, home Saturday.

After one week, I returned to the hospital to have a shell fitted into socket (removable) that was intended to keep the eyelid in shape. They said it may take two or three months before my prosthetic eye was ready. I decided to go back to work 10 days later, after touring various pharmacies in search of a black eye patch. Good move, bad move. 20,000 questions – "What have you done to your eye?" and 20,000 various replies.

Nevertheless, after all these years, I often contemplate on the life that I have lived and sometimes consider that I have been gifted. I see things in a way others may not. It says somewhere in the bible that in the kingdom of the blind the one-eyed man is king. I have many friends who are totally blind and they can see more clearly than I can. It's hard to describe.

Just to finish off, I will shortly be 74 years old, I still drive every day, almost 57 years with a clean driving license and no accidents. I was a keen cyclist, karate student, folk singer, poet (six books), gardener, waiter, active member of the British Red Cross, Blackpool Tram Conductor, Milkman, Paperboy, and served 27 years in British Civil Service.

THE LIGHT OF THE BODY IS THE EYE, AND IF THINE EYE BE SINGLE THEN THINE WHOLE BODY SHALL BE FULL OF LIGHT. God Bless You All



Ethan

RESOURCES FOR PATIENTS, FAMILIES, AND RESEARCHERS

FOR PATIENTS AND FAMILIES:

- **Doctor Directory**
International directory of Coats' Disease specialists.
- **Patient and Family Contact Directory**
Contact list of Coats' patients and parents.
- **Online Collection of Information**
Resources to help navigate a Coats' Disease diagnosis.

FOR CLINICIANS AND RESEARCHERS:

- **Research and Education Grants Available**
- **Coats' Disease Patient Registry**
Anonymized Coats' patient data accessible to researchers.

These resources, and more, can be found at www.coatsdiseasefoundation.org

ABOUT THE FOUNDATION

Our Vision

To find a cure for Coats' Disease

Our Mission

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.

The Foundation 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.



Charles

Kingston

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Make A Donation Today!

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www.coatsdiseasefoundation.org



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Jack McGovern



Coats' Disease Foundation

www.coatsdiseasefoundation.org

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.



Kaydn

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 4 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.



Maddie

OUR IMPACT TO DATE

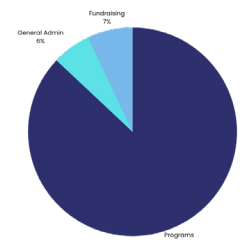
The Foundation focuses on supporting research to discover a cure and providing resources for patients, parents, families, and doctors who face the challenge of Coats' Disease. Our achievements include:

- Currently funding **Research Grants** that focus on Coats' Disease;
- Launching a new phase of **genetic research** into Coats' Disease with biotech leader Genetech;
- **Funding Education Grants** to early career doctors and researchers to inspire them to specialize in Coats' Disease;
- Creating the only **Coats' Disease Patient Registry** in the world for researchers to access patient data;
- Appointing a **Scientific Advisory Board** composed of the country's top Retinal Specialists to provide guidance that advances our vision of finding a cure for Coats' Disease;
- Forming the global volunteer **Coats' Ambassador Network (CAN)** to raise awareness.

HOW TO DONATE

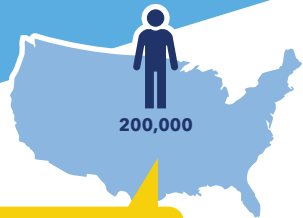
Donations are accepted year-round online at coatsdiseasefoundation.org/donate or by check mailed to Jack McGovern Coats' Disease Foundation, Attn: Joe Galligan, Treasurer, C/O Galligan, Thompson & Flocus, LLP, 1650 Borel Place, Ste 105, San Mateo, CA 94402.

Out of every dollar spent, 94 cents goes directly to support our mission and goals - raising awareness, funding research, and building patient resources.



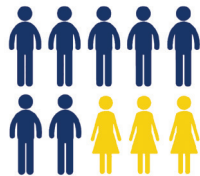
Please join our efforts!

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



200,000

In the US, a rare disease is a disease that affects fewer than 200,000 people.



75%

Estimated percentage of Coats' Disease patients who are male.



2/3

of Coats' patients are diagnosed as children under age 17.



95%

Estimated percentage of Coats' Disease cases that are unilateral (affecting only one eye).



IMPORTANT MATERIALS

New Patient Information Packet

<https://www.coatsdiseasefoundation.org/recently-diagnosed>

Jack McGovern Coats' Disease Foundation Brochure

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

IMPORTANT RESOURCE LINKS

Doctor Directory

<https://www.coatsdiseasefoundation.org/find-a-doctor>

Patient Registry

<https://www.coatsdiseasefoundation.org/patient-registry>

Patient & Family Contact Directory

<https://www.coatsdiseasefoundation.org/community-support>

Mailing List Sign Up

<https://www.coatsdiseasefoundation.org/newsletter>

Become a Foundation Donor

<https://www.coatsdiseasefoundation.org/donate>

**I Fight
Coats' Disease**
What's your superpower?



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