



## NATIONAL RARE DISEASE DAY: FEBRUARY 28, 2019



### *How will you show your stripes?*

The zebra, with its distinctive stripes, is the official symbol of rare diseases in the United States. Because Coats' Disease is part of the rare disease community, we'd like to share some ways to show your support this month (thanks to [NORD](#) for some of these great ideas!).

1. [Share Your Story!](#) If you, or a family member, has Coats' Disease, please share your story on our website. It will help connect you to the Coats' community and inspire others.
2. [Support the Jack McGovern Coats' Disease Foundation](#) with a tax-deductible gift this month. Your gifts enable us to continue fighting for a cure for Coats' Disease!
3. Attend an [advocacy event](#).
4. Change your Facebook profile picture using NORD's [Facebook Profile Picture Frame](#).
5. [Pitch your local media outlets about your Rare Disease personal story](#) using these templates provided by NORD.
6. Spread awareness of Coats' Disease by telling your story on your own social media platforms. Tag us in your posts - Facebook, Twitter, and Instagram!
7. Is it your birthday this month? What better way to celebrate than by [creating your own Facebook birthday fundraiser](#) to benefit the Jack McGovern Coats' Disease Foundation!
8. Nominate your physician for inclusion in our [Doctor Directory](#). This important resource will help others find specialists in their area who are experienced in treating Coats' Disease.

### SPECIAL ANNOUNCEMENT!

The Foundation is pleased to announce the creation of a Scientific Advisory Board!

Stay tuned for more information in our next newsletter...

### DOCTOR DIRECTORY



Until the day that research leads to prevention or a cure, time is of the essence in diagnosing

and successfully treating patients with Coats' Disease.

The Jack McGovern Coats' Disease Foundation Doctor Directory is a resource for patients and their families to swiftly identify preeminent ophthalmologists in their area so they can access quality medical care quickly. We invite you to join us as we work to find a cure for Coats' Disease.

Patients and Physicians are both encouraged to submit information. [Click here to submit online](#). Or, patients can [print a PDF form](#) to take to their next appointment!

### ATTENTION RESEARCHERS AND PRACTITIONERS: TRAVEL GRANTS NOW AVAILABLE!

The Jack McGovern Coats' Disease Foundation is pleased to accept applications for 2019 Travel Grants. These grants are being offered to Pediatric Retina Fellows and/or Pediatric Retina Specialists within their first five years of practice.

Since 2006, the Jack McGovern Coats' Disease Foundation has been working to support the medical community's efforts to investigate the causes of and to improve treatments for Coats' Disease, with the goal of finding a cure. We are offering Travel Grants for young doctors and researchers to attend either the 2019 Association for Research in Vision and Ophthalmology (ARVO) meeting in Vancouver, BC or the 2019 Advances in Pediatric Retina (APR) meeting in Salt Lake City, Utah.

Our vision is to find a cure for Coats' Disease. To achieve this, the Foundation is committed to these four goals: Build Awareness of Coats' Disease; Raise Funds for Research; Fund Research; and Build Patient Resources, such as a Doctor Directory. We have also established a Patient Registry for researchers to access.

By sponsoring travel to conferences for new professionals, we hope to raise awareness about the Jack McGovern Coats' Disease Foundation and our efforts to encourage research into this disease. Please visit our website to learn about Research Grant Opportunities supported by the Foundation for research into Coats' Disease. <https://coatsdiseasefoundation.org/research/apply-for-a-grant/>

The application deadline for the Travel Grants is March 1, 2019. [Download the Grant Guidelines here.](#)

## THE FACES OF COATS' DISEASE: ANDREAS' STORY



About 6 years ago, I had taken my son, Andreas (age 4 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 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, Andreas had 9 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 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. He will remain legally blind in that eye due to the scarring but will lead a normal life (he was most excited 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!

### THANK YOU!

*We want to thank the parents and patients who have shared your stories, photos, and videos with us! [\(Please see "our stories" on our website.\)](#) These stories are powerful reminders of why we established the Foundation and they keep us laser-focused on our mission to raise funds in support of ongoing research and offer all Coats' Disease patients hope and improvements as they wage a lifelong battle against Coats' Disease and blindness. If you would like to share your own Coats' story, please visit our [website](#).*

### FOLLOW US ON SOCIAL MEDIA!

Keep up-to-date with the latest research, learn about events, connect with other Coats' families, and share your experiences.

facebook

twitter



YouTube

## DONATE!

Jack McGovern Coats' Disease Foundation funds research to find a cure for Coats' Disease and pediatric retinal diseases.

Your generous gift enables us to:

- Sponsor events to raise awareness.
- Engage a network of volunteers around the world to help us achieve our mission.
- Offer grants that encourage researchers to explore the causes and search for a cure for Coats' Disease.
- Endow scholarships to Ophthalmologists to inspire them to specialize in Coats' Disease and other rare eye disorders.
- Donate money for research to improve treatments and to find a cure.
- Create and maintain a comprehensive directory of Coats' Disease specialists.
- Expand the Patient Registry as a source of comprehensive, accessible data for researchers.

DONATE THROUGH FACEBOOK - IT'S EASY!!!

facebook

Celebrate your birthday by creating a Birthday Fundraiser to support the Jack McGovern Coats' Disease Foundation. All donations raised go directly to the Foundation.

### SAVE THE DATE!

#### 13th Annual Golf Tournament and Dinner



August 22, 2019  
Crystal Springs Golf Club  
Burlingame, CA

Our annual golf tournament and dinner is our biggest fundraiser of the year.  
*Sponsorships available!*

20 Park Road, Suite E • Burlingame, CA 94010-4443 | 888-314-8853 • [www.curecoats.org](http://www.curecoats.org)

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 taxpayer ID number is 26-2439083.