



January 2019

## Greetings from the Founders: Tina and Ed McGovern



As we look ahead to all of the possibilities in 2019, we thank you all for your support over the past 12 years! We head into the new year with a vigorous focus on our efforts to increase the impact of the Jack McGovern Coats' Disease Foundation and bring us closer to our vision to Find a Cure for Coats' Disease.

As we look forward, we must also celebrate the many successes of 2018. We are proud of the work we have done and vow to continue in our fight to find a cure.

**Build Awareness.** Jack's story was featured in US Lacrosse Magazine to raise awareness of Coats' Disease and send the message to all Coats' patients that they can follow their dreams despite this disease. [See the story here.](#)

We also held our first annual Cure Coats' 5k/1k run in October at the beautiful Sierra Point Marina. [Please see a brief video here.](#)

**Raise Funds.** Thanks to your support, in 2018, we raised over \$190,000 to fund research on Coats' Disease. We are grateful to our volunteer Board Members who generously donate their time and talent to provide services to the Foundation. We are pleased to report that 84% of all funds raised support programs and research to find a cure for Coats' Disease.

**Fund Research.** We partnered with the Wilmer Eye Institute, Johns Hopkins Medicine, in Baltimore, Maryland, to establish the first-of-its-kind Jack McGovern Coats' Disease Foundation National Tissue Biobank. We are continuing that financial support to build a robust resource of tissue for researchers around the world to access in their pursuit of a cure for Coats' Disease.

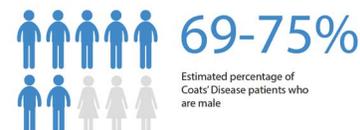
We also continue our support of Genentech which has been conducting genetic research on the causes of Coats'. We are poised to support additional research in 2019.

**Build Patient Resources.** We continue to recruit patients around the globe to add their information to the Patient Registry so that researchers may access anonymized data on Coats' Disease patients. The Patient Registry now includes data from patients in twenty-six countries; that number continues to grow. Many of those patients have nominated their doctors for inclusion in our Doctor Directory. Our goal is that all patients and their families can easily locate an ophthalmologist who has experience in treating Coats' Disease.

We hope you'll continue to support the Foundation in 2019 and on! For more information about the Foundation, please visit our website at [www.coatsdiseasefoundation.org](http://www.coatsdiseasefoundation.org).

## DID YOU KNOW?

### COATS' DISEASE FACTS



## 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!

## THE FACES OF COATS' DISEASE: JACK'S STORY



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 this 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 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. Jack's retina was partially detached and lots of fluid had leaked into his eye. The first laser treatment went really well.

Jack is closely monitored by both Dr. Shapiro and Dr. Kipp; he sees them every 2-3 months. 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 6-year-old who loves to play soccer, basketball, baseball, swim, ski and play with his three siblings. Coats' doesn't slow Jack down!

## 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](#).*

## DONATE!

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

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.

*Make a Difference!*  
**DONATE**

### 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!***