



Coats Disease Foundation
raising funds to support ongoing
research to find a cure



Dear Friends,

As we reflect back on our efforts in 2018 to increase the impact of the Jack McGovern Coats' Disease Foundation, we are so grateful for the support of our Coats' families, friends, and patients around the globe! Together, we have made progress in finding a cure for Coats' Disease, through building awareness, raising funds, funding research, and bringing together doctors and patients. Looking ahead, we promise to continue to focus our efforts on our four goals in order to achieve our vision to *Find a Cure for Coats' Disease*. Please read on to hear of some of the successes of the past year that we will continue to build upon for 2019.

BUILD AWARENES



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.



THE FACES OF COATS' DISEASE

Oliver

"I am so proud of our little man, he never lets Coats' get in his way. He is three now and he can be a little clumsy at times. He forgets he can't see things coming from his right when running about, so lamp posts and doors can sometimes pose a hazard. But, other than that, you would never know... always worry about "what if we come to the stage where it can't be managed anymore, and he has to have his eye removed?" How do you deal with that in a child? But we will deal with it, because we will have no choice." [Read more of Oliver's story.](#)



Eva

"Eva has a normal life, like all Coats' kids... isn't any more clumsy or accident-prone than a normal 5-year-old! She started school in August this year and has had a vision support teacher keeping an 'eye' on her on a termly basis for the last year, which was a referral from the consultant. Although she doesn't appear to require any support at this time, there are many options available should she need support in the future which is great! She is so funny and loving and loves to perform! We certainly don't see anything holding her back!" [Read more of Eva's story.](#)



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 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.

As we look ahead to all of the possibilities in 2019, we thank you all for your support over the past twelve years. Thank you to the parents and patients who have shared your stories, photos, and videos with us this year. ([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.

On behalf of the Jack McGovern Coats' Disease Foundation, we wish you all joyous holidays and a very healthy and happy new year!

Tina and Ed McGovern



P.S. If you have not yet made your 2018 tax-deductible donation, there is still time!

Donate Today!
Click here.

Jeff

"When I was 8... they discovered that I had the late stages of Coats' Disease and there was nothing they could do. Laser surgery was in its early stages in 1992 and my condition was too far gone to perform any medical technique to restore my vision.



I tell those who are diagnosed recently or later in life, who are too late to fix their eye... do not despair. Good things will happen to your body eventually and one should never feel ashamed or embarrassed of the way your eyes look to others. The sooner one embraces Coats' Disease as a way of life, the sooner you can jump into an adventure of helping other parents and kids who are concerned with Coats' Disease... with today's technology, kids have a better chance than ever before to cure Coats' Disease." [Read more of Jeff's story.](#)

Andreas

"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... 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." [Read more of Andreas' story.](#)

Trystn

"Trystn has had two surgeries and so far they have helped tremendously, however, we have a very long road to go. He is in the third stage of Coats' Disease borderline 3b and he has a lot of scar tissue causing the retina to not reattach. Trystn looks like a normal kid and is very brave! He normally doesn't let his eye bring him down. Sometimes it bothers him a lot but it's mainly because he doesn't understand, being that he just turned 5. I know he will do great things, even with one good eye." [Read more of Trystn's story.](#)

