

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.



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:

- **Funding research into Coats' Disease;**
- Partnering with biotech leader Genentech for **Coats' Disease research;**
- **Funding Travel Grants** to junior doctors and researchers to inspire them to specialize in Coats' Disease;
- Creating a **Coats' Disease Patient Registry** and a **National Tissue Biobank** in partnership with the Wilmer Eye Institute, Johns Hopkins Medicine for all researchers to access patient data and tissue;
- 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 a global **Patient and Parent Volunteer network.**

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.



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).

HOW TO DONATE

Donations are accepted year-round online at coatsdiseasefoundation.org/donate, by check mailed to Jack McGovern Coats' Disease Foundation, Attn: Joe Galligan, Treasurer, 630 North Mateo Drive, San Mateo, CA 94401, or by contacting us directly.



ALL DONATIONS ARE USED TO RAISE AWARENESS, FUND RESEARCH, AND PROVIDE PATIENT RESOURCES. PLEASE JOIN OUR EFFORTS!

The Foundation is a California Non-Profit Corporation and a recognized IRS 501(c)(3) charitable organization. All donations are tax deductible. Our EIN is 26-2439083.



RESOURCES FOR PATIENTS, FAMILIES, AND RESEARCHERS

FOR PATIENTS AND FAMILIES:

- **Doctor Directory**

International directory of Coats' Disease specialists.

- **Parent/Patient Community Directory**

Contact list of Coats' patients and parents.

- **Online Collection of Information**

List of *Questions to Ask Your Doctor*, Coats' Disease Information Sheet, and the latest research on Coats' Disease.

FOR CLINICIANS AND RESEARCHERS:

- **Coats' Disease Patient Registry**

Anonymized Coats' patient data accessible to researchers.

- **Jack McGovern Coats' Disease Foundation National Tissue Biobank**

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.



Coats' Disease Foundation



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