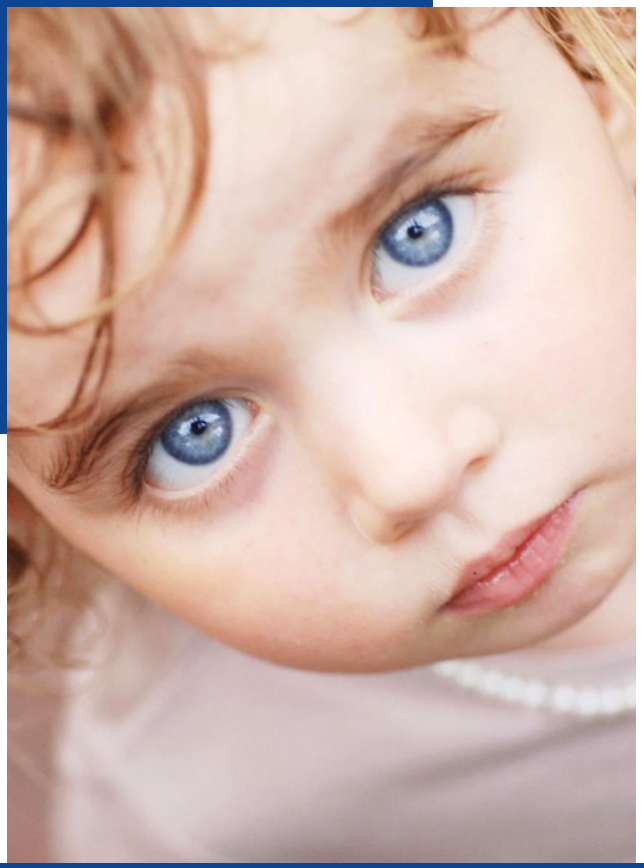
Mission

The Cure Blau Syndrome Foundation is a network of parents, patients and collaborating scientists and doctors. We aim to 1) fundraise and foster steps toward a cure and effective treatment options, 2) increase awareness among medical professionals and scientists and 3) provide education and advocacy opportunities for our Blau Syndrome community.

"Rare diseases are not rare - collectively, they affect millions of people around the world. While each disease may be unique, those who are affected by rare diseases share a common bond in their strength, resilience, and hope for a better future."



What is Blau Syndrome

Blau Syndrome is a rare degenerative and life-threatening disease that robs those affected of their vision, mobility and in some cases their life. The condition is caused by mutations in the NOD2 gene, which provides instructions for making a protein involved in the immune system and manifests before the age three. There is no cure for Blau Syndrome and the disease can be diagnosed through a simple blood test.

Get in Touch with us!

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Cure Blau Syndrome Foundation

Cure Blau Syndrome

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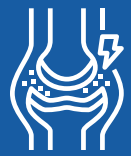
Key Features

Blau syndrome is a rare degenerative and life-threatening disease that robs those affected of their vision, mobility and in some cases their life.

Uveitis

Uveitis is a common and often severe symptom of Blau Syndrome that can lead to vision loss and other complications that affects 80% of patients.

Granulomatous Arthritis



96% of patients have arthritis and tenosynovitis, often beginning in infancy.

Skin Rash

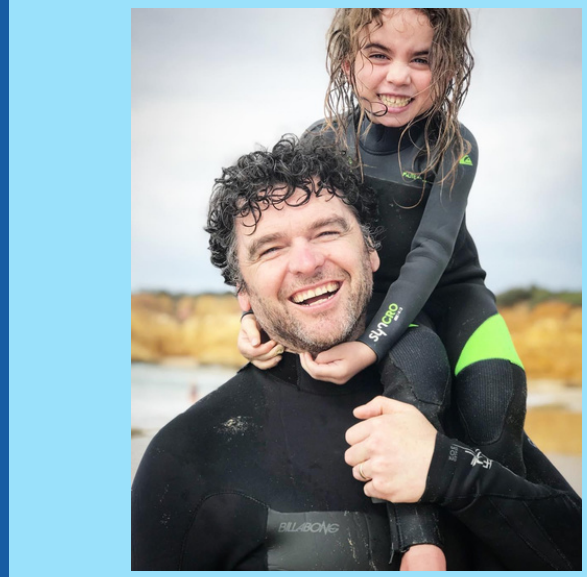
Usually the earliest sign of Blau Syndrome, granulomatous dermatitis can be found in 90% of patients.

Organ Involvement

Expanded manifestations of the disease can include inflammation in the kidneys, liver, brain, heart, spleen, blood vessels, blood vessels and lymph nodes.

Research Support

Fundraising campaigns allow our Foundation to fund international projects investigating the pathogenesis of Blau with application to treatment practices. We prioritize building bridges between the patient and scientific communities.



Our Inspiration

My daughter, Lexi, was the original inspiration and founder of the Cure Blau Foundation. We ran out of time before we could find a cure for Lexi, but we carry on in her legacy for those who continue their battles with Blau.

There is currently no effective treatment for Blau. While our ultimate goal is a gene therapy and cure for Blau syndrome, we are exploring all options for an effective treatment.

Every dollar matters. Every hour matters. Every voice matters. We all have the potential to help change the lives of those affected by Blau syndrome. Your donation of funds or volunteer hours can help us make medical history. Even just sharing our story will make a big difference.

Help us turn hope into action to find a cure for this horrible disease.

Troy Townsin, Founder & Board Member

Education and Awareness

After a rare disease diagnosis, finding information and community can be a challenge. The Cure Blau Syndrome Foundation hosts free virtual educational opportunities that bring the patient, scientific and medical communities together. Our website houses a comprehensive database of academic literature on Blau Syndrome and individualizable supports for pediatric patients experiencing medical procedures.

Get involved!

- Join our patient registry
- Donate to our bio-blood bank
- Volunteer for a research study
- Follow us on social media
- Share your story!