

About the Association

A Rare Community

The Histiocytosis Association is a global nonprofit organization dedicated to addressing the unique needs of patients and families dealing with the effects of histiocytic disorders while leading the search for a cure. It is the only organization of its kind, connecting the patient and medical communities to:

- » Grow and share knowledge of histiocytic disorders
- » Provide critical emotional and educational support to patients and families
- » Identify and fund key research initiatives that will lead to a world free of histiocytic disorders

The Road to a Cure

The Histiocytosis Association is among the world's leading financial supporters of scientific research into histiocytic disorders. Each year the Association conducts a comprehensive and rigorous grant proposal process, and with the guidance of experts, identifies the most important and promising research studies to receive funding.

Community Outreach

While the search for more effective treatments and a cure continues, the Histiocytosis Association is dedicated to supporting and empowering the patients and families who live with these diseases every day.

Funding the Association

Histiocytic disorders are considered "orphan diseases." An orphan disease is one that affects less than 200,000 individuals in the United States.* Subsequently, these disorders do not receive a high priority for government-funded research. The Association relies on contributions from corporations, foundations and individual donors to fund critical research, build awareness and conduct community outreach initiatives.

*Rare Disease Act of 2002

You are not Alone

While the search for more effective treatments, and ultimately a cure continues, the Histiocytosis Association is dedicated to informing and empowering those who live with histiocytic diseases every day.

Whether newly diagnosed and learning to navigate this rare diagnosis or searching for strength and support while caring for a loved one, you can turn to the Histiocytosis Association to connect you with a community who understands what you are going through.

The Histiocytosis Association invites you to become a part of this our rare community. We encourage you to explore our online resources by visiting our website:



www.histio.org

Making a Donation

All donations are tax deductible (Federal Tax ID # 22-2827069). Visit www.histio.org/donate to join us in the pursuit of a cure.

HISTIOCYTOSIS  **ASSOCIATION**
A Rare Community

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ROSAI-DORFMAN DISEASE

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What is Rosai-Dorfman disease?

Rosai-Dorfman disease (RDD), also known as sinus histiocytosis with massive lymphadenopathy (SHML), is a rare histiocytic disorder which involves the over-production of a type of white blood cell called non-Langerhans sinus histiocyte.

RDD is characterized by accumulation of abnormal cells (histiocytes) in various tissues/organs of the body. RDD tends to affect skin and lymph nodes most commonly, although any organ system can be involved from head to toe. The reason that these cells over-produce is not known, although many possibilities have been considered, including viral, bacterial, infection, environmental, and genetic causes.

In 1969, two pathologists, Juan Rosai and Ronald Dorfman, reported a distinct histiocytic disorder in several children with massive enlargement of the lymph nodes, as well as other symptoms. They named this condition sinus histiocytosis with massive lymphadenopathy, and the name has since come to be known as RDD. In the last decade, cancer-causing genetic changes (mutations) in the MAP kinase pathway have been identified in 50% of cases with RDD. Therefore, RDD was recognized as a blood cancer by the World Health Organization in 2022.

However, RDD is usually not life-threatening, and many patients do not require treatment.

The exact incidence of RDD cases is not known, although it does occur worldwide and seems to affect equal numbers of males and females. It can affect children as well as adults. The discovery of mutations has revolutionized the care of patients with severe RDD, resulting in targeted treatments that have the ability to improve patient survival.

Patients with RDD can have chronic symptoms like pain, tiredness, anxiety that need to be managed

alongside. Among patients with involvement of critical organs or symptoms, the prognosis has continued to improve with introduction of targeted drugs. It is important for patients to continue to follow up with their healthcare provider to ensure no complications such as second cancers or side effects of treatment develop. Notify your healthcare team if there is development of any new symptoms.

Symptoms of RDD

- » Skin Nodules
- » Lymph node enlargement
- » Fever
- » Paleness/anemia
- » Weakness
- » Weight loss
- » Shortness of Breath
- » Nosebleeds
- » Blockage or discharge of the nose
- » Eye bulging/decreased vision
- » Inflammation of the tonsils/sinuses

How is RDD Treated?

Not all patients will require treatment at diagnosis. Some patients may have waxing and waning disease that does not interfere with life expectancy or symptoms, and close monitoring (wait and watch) strategy can be utilized, with institution of treatment at the onset of symptoms or involvement of one of the internal organs. RDD involving a single-site or organ can be treated by surgery or local treatments (injections, creams, ointments). Patients with RDD involving more than one site or organ should have their treatment planned by a team. The treatment approach for multi-system RDD has evolved significantly due to discovery of mutations in the MAPK pathway genes, leading to the successful use of targeted therapies.

To learn more about the Association and its Scientific Initiatives, Outreach Efforts and Research Program visit www.histio.org.



The Histiocytosis Association is dedicated to raising awareness about histiocytic disorders, providing educational and emotional support, and funding research leading to better treatments and a cure.

A world free of histiocytic disorders.

www.histio.org