

## 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

## Registering with the Association

Registering with the Histiocytosis Association is free of charge. All those interested in or dealing with the effects of histiocytic disorders are welcome to join. After registering, you will receive:

- » A subscription to the Association's eNewsletter
- » Special updates about histiocytic disorders research
- » Invitations to local, regional and national events
- » Exclusive access to the online Histo Physician Directory, Histo Warriors Directory and Online Discussion Groups
- » Announcements about upcoming educational meetings

Most importantly, you will have the opportunity to connect with the more than 7,000 members worldwide that have come together in the fight against histiocytic disorders.

The Histiocytosis Association invites you to become a part of the Histo Community. Visit [www.histio.org/join](http://www.histio.org/join) and join today.

### Making a Donation

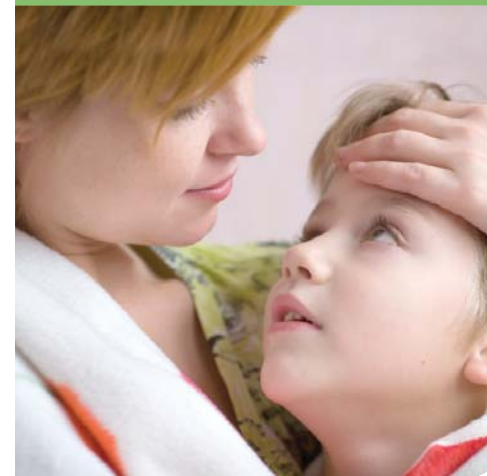
All donations are tax deductible (Federal Tax ID # 22-2827069). Visit [www.histio.org/donate](http://www.histio.org/donate) to join us in the pursuit of a cure.

HISTIOCYTOSIS  ASSOCIATION®  
A Rare Community

Histiocytosis Association  
332 North Broadway | Pitman, NJ 08071 USA

Phone: +1 856-589-6606 | Fax: +1 856-589-6614  
[www.histio.org](http://www.histio.org) | [info@histio.org](mailto:info@histio.org)  
Federal Tax ID # 22-2827069

Published by the Histiocytosis Association  
in partnership with the Histiocyte Society



JUVENILE XANTHOGRANULOMA

HISTIOCYTOSIS®  
ASSOCIATION  
A Rare Community

## What is Juvenile Xanthogranuloma?

Juvenile xanthogranuloma, also known as JXG, is a rare, non-Langerhans cell histiocytosis that is usually benign and self-limiting. It occurs most often in the skin of the head, neck, and trunk; it can also occur in the arms, legs, feet, and buttocks. JXG can affect the eye, most commonly in young children with multiple skin lesions. Less commonly, JXG may involve locations such as the lung, liver, adrenal gland, appendix, bones, bone marrow, pituitary gland, central nervous system, kidney, heart, small and large intestines, and spleen.

JXG involves the over-production of a kind of histiocyte called a dendritic cell (not a macrophage). These cells then accumulate and lead to various symptoms, depending on location. The cause of this disease is not known.

JXG mainly affects infants and small children with an average age of 2 years; however, it can also occur in adults of all ages. Most frequently, it presents as a single skin lesion which varies in size; children less than 6 months of age are more likely to have multiple lesions. It occurs at birth in about 10% of patients, and more males



*To learn more about the Association and its Scientific Initiatives, Outreach Efforts and Research Program visit [www.histio.org](http://www.histio.org).*

are affected than females. When JXG occurs in adults, it tends to be more complicated and is not known to spontaneously improve. The total number of patients with JXG is not known, but it may be higher than reported since this disease is sometimes misdiagnosed or may spontaneously improve in children.

## Symptoms of JXG

Symptoms of JXG may include

- » Reddened, yellowish or brownish, slightly raised, and rubbery bumps on the skin
- » Abnormalities in blood counts
- » Abnormalities in blood liver tests
- » Elevated inflammation level (sedimentation rate) in the blood
- » Potentially diabetes insipidus

## How is JXG treated?

Patients with minimal lesions usually need no therapy. Surgical removal may be undertaken for several reasons: to obtain a biopsy for diagnosis; when there is an organ-function problem because of disease; for cosmetic reasons; or to remove scar tissue. Apart from these reasons, skin-only JXG in children is usually observed without therapy. For patients who have symptomatic or rapidly growing disease, treatment with chemotherapy or low-dose radiation has been reported, although there is no standard treatment that is agreed upon. With eye involvement, steroids may be applied to the surface of a lesion, injected, or taken in pill form. Rarely low dose radiation treatment may be given to prevent visual loss.

*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](http://www.histio.org)**