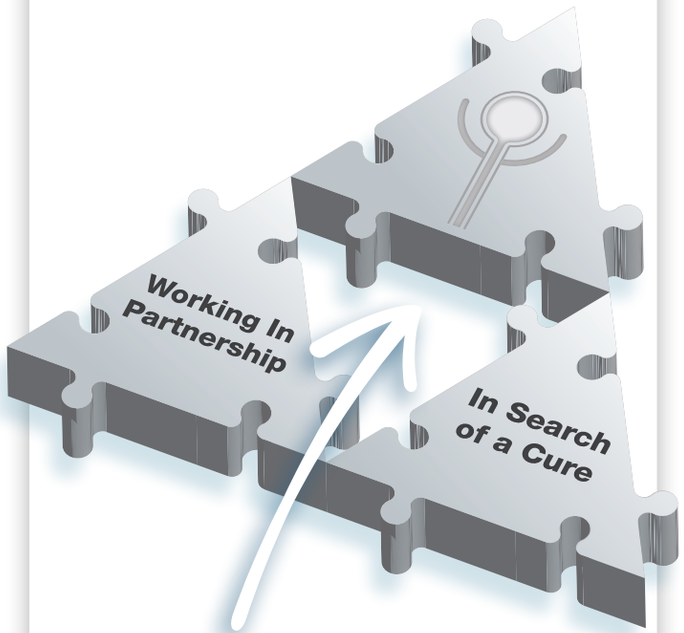
GET Involved and help us make a difference

Research into LCH and HLH has been very limited due to lack of funds and has been the result of donations and fundraising. In order to find a cure as well as provide practical support for both patients and their families, we need to continue raising as much money as we can. By working together and raising money, we can achieve this.

There are several different ways in which you can help us make a difference. You may want to consider either organising a fundraising event, a regular gift, payroll giving, taking out a subscription, a one-off donation, a gift in celebration, a gift in memory or leaving a legacy.

www.histiouk.org/all-ways-to-get-involved/



The funding gap

How & where to contact us

For further information about Histio UK, Volunteering, Fundraising or Research please call or visit: **www.histiouk.org**

Head Office: +44 (0) 7850 740 241

Email: Histio@HistioUK.org

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Histio UK & Histio Champions UK

@HistioUK

We are dependent on your involvement and your generosity

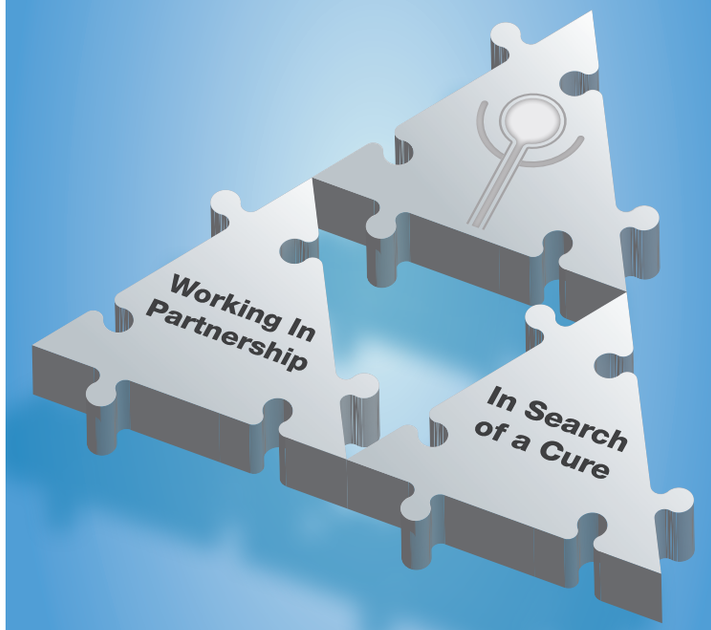
Will you help us complete the puzzle?

Together we will find a cure

www.HistioUK.org

Registered in England & Wales. Charity Number: 1158789

Together we are Histio UK



Together we will find a cure

Who we are

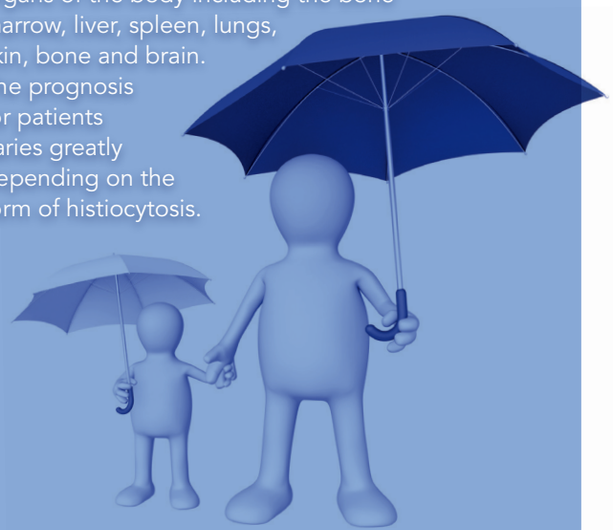
Histiocytosis UK is a registered charity dedicated to promoting and funding scientific research into uncovering not only the causes of all histiocytic diseases, which include Langerhan's Cell Histiocytosis and Haemophagocytic Lymphohistiocytosis, but also ensuring early diagnosis, effective treatment and a cure.

The Charity aims to support patients and their families as well as raise public and professional awareness of histiocytic disorders. Its team of Trustees include the UK's leading paediatric LCH and HLH specialists.

Histio UK is closely linked to the Nikolas Symposium, The Artemis Association, The Histiocyte Society, Euro Histionet and The Histiocytosis Association.

What is Histiocytosis?

Histiocytosis is an umbrella term applied to a group of rare diseases, characterised by increased numbers of white blood cells called histiocytes in the blood and tissues. In all forms of histiocytosis, these cells, which are part of the protective immune system, begin to attack the body, targeting many organs of the body including the bone marrow, liver, spleen, lungs, skin, bone and brain. The prognosis for patients varies greatly depending on the form of histiocytosis.



There are two main groups.

The **first group** is called a dendritic cell disorder, and the most common disease in this group is **Langerhans Cell Histiocytosis (LCH)** previously known as Histiocytosis X. Also included in this group are more rare diseases, Juvenile xanthogranuloma (JXG) and Erdheim-Chester Disease (ECD).

Langerhans Cell Histiocytosis, LCH for short.

Histiocytes called Langerhans cells, which are normally found in the skin, may spread to many organs and damage them, so the symptoms vary depending on which organs are affected, but skin rashes, destruction of bone, breathing problems and damage to the brain are common.

LCH occurs in children, often during infancy but also in adults. It is usually a chronic disease and may cause severe disabilities due to brain damage. The diagnosis is made by microscopic examination of a tissue specimen obtained by biopsy. The prognosis depends very much on the extent of disease and organs affected, which can be assessed by imaging studies. LCH is thought to be caused by alterations in the DNA of Langerhans cells.

Juvenile xanthogranuloma (JXG)

Juvenile xanthogranuloma, also known as JXG, is a rare, non-Langerhans-Cell Histiocytosis that is usually benign and self-limiting. This disease may have been first reported by Rudolf Virchow in 1871 and again in 1905 by H.G. Adamson. In 1954, it was named juvenile xanthogranuloma to reflect the appearance of the cells under a microscope.

Erdheim-Chester (ECD)

Erdheim-Chester disease is a rare form of non-Langerhans-Cell Histiocytosis. It involves the excessive production of histiocytes, which are a type of white blood cell. These cells, which normally help fight infection and injury, then gather in different organs and tissues and can result in a variety of symptoms, including organ failure.

The **second group** is called a macrophage cell disorder, and includes primarily:

Haemophagocytic Lymphohistiocytosis (HLH) and Rosai-Dorfman Disease (RD).

Haemophagocytic Lymphohistiocytosis, HLH for short.

In this disease a virus infection triggers another type of histiocyte, the macrophage, to become over active and attack the body. Red blood cells and other white blood cells are engulfed and destroyed by the macrophages, so that the patient is unable to fight infections.

Patients therefore suffer from high fevers, may become anaemic and often have skin rashes, as well as symptoms due to the infecting virus. HLH is an acute and life threatening disease. It frequently occurs in childhood but may occur at any age.

Diagnosis depends on detection of the infecting organism and demonstration of macrophages engulfing other cells as well as other abnormalities of white blood cells, usually in sample of bone marrow. In familial forms of HLH, abnormal genes, which alter white blood cell function, are passed from the parents to children.

Rosai-Dorfman disease (RD)

Rosai-Dorfman disease (RD), 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-cell sinus histiocytes.

Our Goals

- To further scientific research into histiocytosis
- To raise awareness of all histiocytic diseases
- To develop a more accurate means of diagnosis
- To facilitate knowledge transfer and promote collaboration