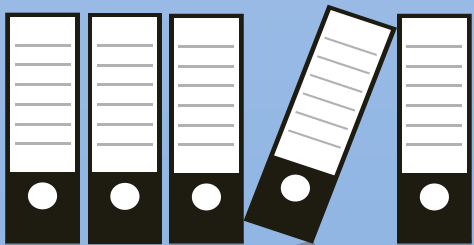


USEFUL LINKS



Introduction

Despite the misery it causes, Histiocytosis is too rare a disease to have generated substantial research in medical circles. Unfortunately, for every child or adult fighting for his or her life, the pain and suffering are just as severe for children and adults afflicted with other better known disorders receiving funding.

For the children and adults battling these illnesses, there is now reason to hope. To ensure the research continues, we ask for your help, to complete the funding puzzle.

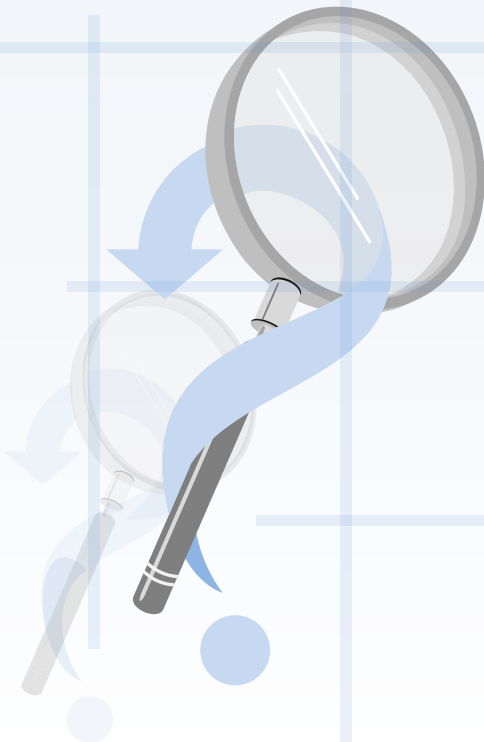
Our awareness and research programmes provide a beacon of hope for the many children and adults battling Histiocytosis, to ensure this research continues we ask you to pledge your support.

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WHAT IS HISTIOCYTOSIS

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.

Please be advised that all the information you read in this document is not a replacement for the advice you will get from your consultant and their team.



WHO WE ARE

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 Langerhans Cell Histiocytosis and Haemophagocytic Lymphohistiocytosis, but also ensuring early diagnosis, effective treatment and a cure.

The Charity aims to support patients and their families by means of information and awareness 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.

Histiocytosis UK Registered in England & Wales. Charity No. 1158789.

Email: Histio@HistioUK.org . www.histiouk.org



Histiocytosis Association of Canada

Histiocytosis Association of Canada,
Box 29095, Okanagan Mission RPO, Kelowna, B.C., V1W 4A7 Canada
Phone: 250-764-6104
Email: histio.canada@shaw.ca
Website: <http://www.histiocytosis.ca>

Artemis Association



The Artemis Association is a group of parents, patients, doctors and friends based in Greece. Its objectives include supporting patients and their families, encouraging and supporting research and keeping up to date with the latest treatments.

Phone: +30 210 45 20 453
www.histioartemis.gr

Nikolas Symposium



The Nikolas Symposium is an annual scientific conference hosted in Greece and funded by the Kontoyannis family in honour of Nikolas Kontoyannis who had severe multi-system LCH as a child and lives with the late effects of the disease. The symposium brings together scientists, pathologists and clinicians in search of a rational cure for the Histiocytic disorders.

Phone: +30 210 45 20 453
www.niksym.org

LCH Belgium



Een onafhankelijke patiëntenvereniging voor kinderen en volwassenen met de ziekte Langerhanscelhistiocytose

info@lch.be
www.lch.be

ASSOCIATIONS, SOCIETIES & REFERENCE NETWORKS

Histiocytosis Association (HA)



The HA is based in the United States and is dedicated to raising awareness about histiocytic disorders, providing educational and emotional support, and funding research leading to better treatments and a cure. **Phone: +1 856 589 6606** **www.histio.org**

Histiocyte Society



The Histiocyte Society is a group of more than 200 physicians and scientists from around the world committed to improving the lives of patients with histiocytic disorders by conducting clinical and laboratory research into the causes and treatment of these diseases.

Phone: +1 856 589 6606 **www.histiocytesociety.org**

Histio Net



This is a reference network for Langerhans Cell Histiocytosis and associated syndromes. Several partners – medical experts in the field of care for Langerhans Cell Histiocytosis (LCH), patients and support groups from the European Union (EU) and from outside the EU – cooperates to share and disseminate knowledge and experience. Their objective is to participate in improving care of patients with LCH and other rare diseases belonging to the same 'family' of diseases.

www.eurohistio.net

CCLG (Children's Cancer and Leukaemia Group)



CCLG is the UK professional body for those working in the area of childhood cancer. LCH is usually treated by this group of clinicians and the CCLG hosts a Histiocytosis Interest Group which has specific expertise in LCH. The CCLG produces a variety of leaflets (e.g. 'A Guide to Clinical Trials – For Parents and Young People', 'How to help brothers and sisters'), all of which are available online and in hard copy. The CCLG website has numerous links to other sites that may be useful.

Phone: +44 116 249 4460 (Main Office) **www.cclg.org.uk** <http://www.cclg.org.uk/family-focus/tips-on-coping>

Erdheim Chester - www.erdheim-chester.org

International Rare Disorders registry

<http://www.histiocytesociety.org/IRHDR?erid=1030169&trid=b2801c30-f354-4545-9321-32dad916b102>

Macmillan



Macmillan provides practical, medical and financial support for families and promotes and campaigns for better cancer care.

Macmillan also helps patients and their families with LCH and has a range of booklets and leaflets available (including information on LCH and chemotherapy).

Ask Macmillan: +44 808 808 00 00 www.macmillan.org.uk

CLIC Sargent



CLIC Sargent is a UK cancer charity for children and young people (up to the age of 25 years), and their families. They provide clinical, practical, financial and emotional support and aims to help the whole family deal with the impact of the disease.

Free Child Cancer Helpline:

+44 800 197 0068 9am-5pm (UK) www.clicsargent.org.uk

Family Fund



<http://www.familyfund.org.uk/>

Carepages



Carepages websites are free patient blogs that connect family and friends during a health challenge.

www.carepages.com

Caringbridge



Caringbridge provides free websites that connect family and friends during a serious health event. You can share health updates, and receive messages of support. www.caringbridge.org

Citizens Advice Bureau

Can advise on employment issues. www.citizensadvice.org.uk

CancerCare



The therapeutic support and information services we offer can help individuals and their families come to terms with and manage the challenges of a serious illness. www.cancercare.org.uk

Teenage Cancer Trust



Our vision is a future where young people's lives don't stop because they have cancer. We make sure they're treated as young people first, cancer patients second and everything we do aims to improve their quality of life and chances of survival. www.teenagecancertrust.org

Sibs



Sibs is the UK charity representing the needs of siblings of disabled people. Siblings have a lifelong need for information, they often experience social and emotional isolation, and have to cope with difficult situations. <http://sibs.org.uk/>

Kids Health - Website about children and parenting offering support and advice on caring for seriously ill children. Look at Tough Topics in the Parenting section. www.kidshealth.org.uk

BACP - British Association for Counselling and Psychotherapy can help to find a private therapist in your area. www.bacp.co.uk

Relate - Counselling, support and information for all relationships. <http://www.relate.org.uk/>

Institute of Fundraising- <http://www.institute-of-fundraising.org.uk/guidance/about-fundraising/>

Health & Safety Executive- <http://www.hse.gov.uk/risk/index.htm>

Food Standards Agency- <http://www.food.gov.uk/business-industry/guidancenotes/#.U85Izssg9jo>

Information Commissioners Office-<http://ico.org.uk/>

Gambling Commission- <http://www.gamblingcommission.gov.uk/>