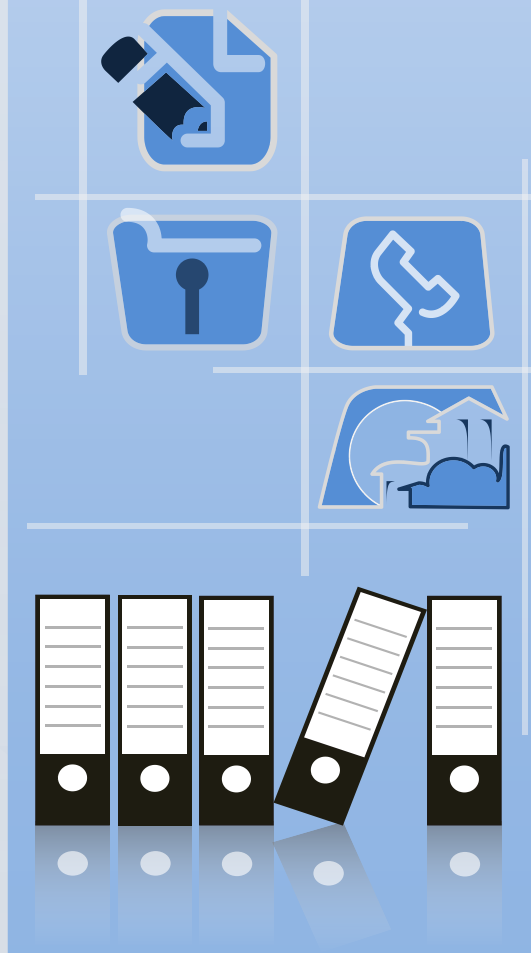
Together we are Histio UK.org

GET INVOLVED
Corporate Partners



Histiocytosis UK

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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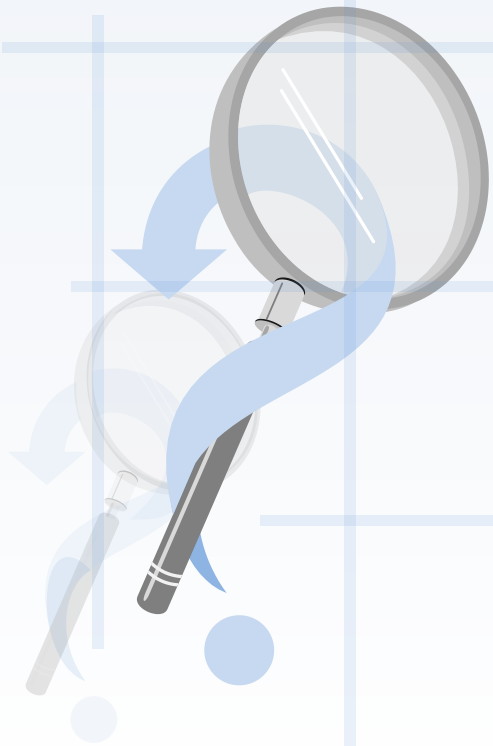

What Is Histiocytosis

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?

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.

Get Involved

There are many ways for your company to work with Histiocytosis UK and make a huge difference to the lives of children, young people, adults and families affected by histiocytosis.
You can get involved through Charity of the Year partnerships, cause related marketing, sponsorship opportunities and more.

How your company can help?

Histiocytosis touches the lives of not just children, young people and adults, but parents, siblings, aunts and uncles, schools, friends and the wider community. Our cause will resonate with your staff, your customers and your clients.

Charity partnerships

We can help your company achieve its corporate social responsibility and marketing objectives whilst offering excellent fundraising, PR and team opportunities. We have fundraising for all to get involved in, from 60-mile challenges, abseils and overseas treks to cake bakes, swap shops and fancy dress days! We will work with you to develop an exciting calendar of events and a communication plan to help us maximize the partnership potential.

Corporate Sponsors

There is just one piece of the puzzle missing!
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 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.

Our Research Goals

- To facilitate the development of gene therapy for HLH patients
- To further research on genetic changes in LCH
- To proceed to clinical trials of drugs targeted to the BRAF mutation

Our Objectives

- The promotion and furtherance of scientific research into the physiology and pathology of histiocytes and the aetiology of histiocytocytic diseases.

- The development of more accurate means of diagnosis, improved protocols for management of patients and ultimately measures for prevention of histiocytic diseases.
- The provision of information in support of patients and families affected by histiocytosis.

Working In Partnership

Research:

With regard to research, being a relatively small charity it does take us some time to build a research fund.

We do not receive grants from the government or corporates and in the main rely on fundraisers such as yourself to help us achieve progress.

We anticipate that our next call for Research Projects requiring funding will be June 2016, once received theses are evaluated by the Scientific Review Board who recommend to our Board of Trustees the projects for funding.

Information Sharing:

In 2015 Histio UK delivered the very first UK Clinicians Forum on Histiocytosis in Leeds with many of their Consultants attending as well as from across the country. We hope to alternate location in the coming years.

Currently we are working on a program for General Practitioners to aid the early diagnosis of histioctic disease. It is hoped that following this we may be able to produce a training guide for Junior Doctors and Consultants to aid diagnosis, treatment and late effects of the disease.

We also contribute to and promote the International Rare Histiocytic Disorders Registry, which facilitates a uniform diagnosis of the RHDs, as well as the collection and analysis of the clinical, epidemiological, treatment and survival data of patients with RHD. It also provides expert pathology reviews and may lead to future therapeutic recommendations. Furthermore, it can provide a framework for future clinical trials, thus creating excellent research opportunities. Lastly, a de-identified link between clinical data and companion biology studies may be accomplished in the future. This may further help in understanding the etiology of these rare diseases, as well as identifying potential therapeutic targets.

2012-In 2012 we committed £327,000 over three years to a collaborative project at the Centre for Molecular and Cellular Biology of Inflammation, Kings College London and the Institute of Cellular Medicine, Newcastle, led by Professor Frederic Geissmann and Dr Matthew Collin.

The project will build on the recent important discovery of a genetic mutation in half of LCH samples tested.

Interim Update

Professor Geissmann and Dr Collin have made good progress in setting up the model system they will use to study signaling in BRAF V600E positive cells and this work is expected to identify additional molecules that may be drug targets. They have already identified new mutations in BRAF itself.

Satoh T, Smith A, Sarde A, Lu HC, Mian S, Trouillet C, Mufti G, Emile JF, Fraternali F, Donadieu J, Geissmann F. Apr 10B-RAF mutant alleles associated with Langerhans cell histiocytosis, a granulomatous pediatric disease. PLoS One. 2012; 7: e33891.

2009-In 2009 we allocated £220,954 to fund a ground-breaking project with the Institute of Child Health at University College London. The project model investigated ways of introducing a normal Perforin gene – the gene most commonly affected inherited HLH – into white blood cells.

Outcomes

Professors Bobby Gaspar and Adrian Thrasher together with Dr. Marlene Carmo, who was funded by the grant, demonstrated that they can successfully introduce a normal perforin gene into mouse stem cells. These stem cells restore normal lymphocyte function when introduced into mice that have an abnormal perforin gene and usually develop HLH. Professors Caspar and Thrasher are now planning to develop this form of gene therapy to restore normal immune function in patients suffering from HLH.

2005-In 2005 we committed £150,000 funding a major three-year research project at the University of Lausanne, Switzerland, led by Professor Hans Acha-Orbea. The aim of the project was to identify genes that are switched on when normal dendritic cells, which are closely related to Langerhans' Cells, become tumours.

Outcomes

Professor Acha-Orbea used a virus to carry a tumours forming gene into mouse dendritic cells which went on to become dendritic cell tumours. He identified genes that are switched on or off as normal dendritic cells become dendritic cell tumours, and that might be targeted to kill abnormal dendritic cells. He plans to go on to search for these genes in human Langerhans Cell Histiocytosis samples. The cell lines continue to provide a resource for understanding normal and abnormal dendritic cells.

Steiner QG, Otten LA, Hicks MJ, Kaya G, Grosjean F, Saeuberli E, Lavanchy C, Beermann F, McClain KL, Acha-Orbea H. In vivo transformation of mouse conventional CD8alpha+ dendritic cells leads to progressive multisystem histiocytosis. Blood. 2008; 111: 2073-82.

Fuertes Marraco SA, Grosjean F, Duval A, Rosa M, Lavanchy C, Ashok D, Haller S, Otten LA, Steiner QG, Descombes P, Luber CA, Meissner F, Mann M, Szeles L, Reith W, Acha-Orbea H. Novel murine dendritic cell lines: a powerful auxiliary tool for dendritic cell research. Front Immunol. 2012; 3: 331.

Payroll giving

Easy to set up and simple to manage, payroll giving is an effortless and tax-effective way for staff to support Histio UK help children, young people and adults with histiocytosis, and their families, the whole year round.

Event Sponsorship

Sponsorship is a fantastic way to support Histio UK whilst achieving a route to market and generating great brand awareness amongst your customers and our supporters.

Cause Related Marketing

CRM is a fantastic way to promote your brand and raise money and awareness for the vital information and research that Histio UK provides. Research from Business in the Community shows that 86% of consumers are more likely to buy a product that is associated with a cause or issue and 73% of consumers would switch brands. A CRM partnership with Histio UK will enable your company to connect with customers, gain a great presence in the community and engage with new audiences.

How we will support you

We will work closely with you to meet your aims and objectives.

Benefits for your company

Get involved in your community

- Link to a UK-wide charity
- Build deeper networks with your audience by providing direct support to the communities your company operates in

Motivate your colleagues

- Encourage team-building, boost employee morale and build loyalty
- Give employees the opportunity to take part in volunteering, expeditions and exciting events
- Engage your customers or clients in fundraising activities

Enhance your brand

- Build rapport with your target audience
- Reach a potential new audience
- Build your reputation as a socially responsible company
- Generate positive PR opportunities at a local and national level

- Be associated with a respected UK-wide charity

How to get involved

We would be delighted to hear from you if you want to discuss how your company can become involved. Please get in touch – call 07850 740241 or email histio@histiouk.org