

together
we will find
a cure



A Search for a Rational Cure



together
we will find
a cure

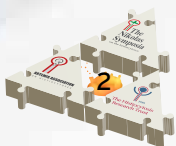
Who we are

The Nikolas Symposium, the Artemis Association and the Histiocytosis Research Trust are individual charitable schemes that act as a unit. They raise awareness and manage vital funds for research projects on Histiocytoses.

What we do

We support patients by giving them information on where to obtain the best possible treatment in their locality and send them written information about the disease. We support community schemes to provide vital advice to newly diagnosed patients even before they contact us.

We bring together doctors and scientists to promote understanding of Histiocytoses and initiate novel research projects. We fund research projects that aim to improve the lives of patients through improved diagnosis, treatments and discovery of rational cures.



What are Histiocytoses?

Histiocytoses are a group of rare diseases that result from abnormalities in the function of histiocytes, the cells in our immune system that normally prevent infections. There are two main diseases: Langerhans Cell Histiocytosis (LCH) and Haemophagocytic Lymphohistiocytosis (HLH).

In LCH, histiocyte, which are normally found in the skin, form collections in many organs and damage them. The most common problems are bony lumps or pain in the limbs and skin rash which can cause large, weeping, raw areas. The disease may affect the lungs, making breathing difficult. It may involve the bone marrow, making it difficult for a person to manufacture enough healthy blood cells. It was affect the liver and spleen, which can be fatal. The disease is often chronic and in some patients it may invade the brain, resulting in long-term disability. Although children are often affected, recently it has become clear that adults also suffer from the disease but are often misdiagnosed.

In HLH, another type of histiocyte, called a macrophage, engulfs and destroys red blood cells and other white cells, leaving the patients vulnerable to infection. Often there is a high fever with rashes, anemia and bleeding causing patients to rapidly deteriorate. Treatment often requires a bone marrow transplant, but even so almost half of the patients die. Most patients are children but the disease can occur at any age.

Along with the physical pain associated with the disease, children and adults also face the emotional suffering of long hospital stays away from home and the fear of not knowing what will happen to them. The stress devastates parents and other family members.

Despite the misery they cause, Histiocytoses have not generated substantial research in medical circles because they are very rare diseases. Unfortunately for every child or adult fighting for his or her life, the pain and suffering from Histiocytoses is just as severe as that from other better known disorders receiving major research funding.

The Nikolas Symposium



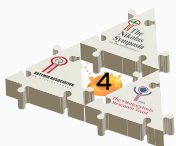
The Nikolas Symposium is a scientific Symposium aiming at identifying rational treatments for Histiocytic Diseases. It was established in 1987 by Apostolos and Elizabeth Kontoyannis, whose son, Nikolas was diagnosed with Langerhans Cell Histiocytosis, as an infant.

The meetings bring together clinicians and scientists in an informal setting designed to promote open and intensive discussion. Each symposium focuses on a single scientific topic of relevance to LCH & HLH pathogenesis and up to 35 scientists and clinicians from across the world are invited.

The Symposia are held annually in May in Athens. The scientific programme is organised by a Steering Committee whose members are elected for a five-year term. Members of the Steering Committee include the Chairman of the Histiocyte Society (an International scientific society devoted to the study of these conditions) and the Chairman of the Histiocytosis Association, which is a parent and patient support organisation based in the USA.

Over the years, the Symposia have originated many concepts and research questions, which have been stimulated research on Histiocytoses all over the world. To promote this, the proceedings of the Symposia are made available to the scientific community through the website.

The Nikolas Symposia have led the way in the scientific effort to find a rational treatment for Histiocytoses. They have provided a model for promoting the study of rare diseases by bringing together doctors concerned for the wellbeing of their patients with leading scientists able to apply the most up to date and powerful techniques to unravel the problems posed by these enigmatic disorders. www.niksym.org





ARTEMIS ASSOCIATION
ON HISTIOCYTOSSES

Apostolos Kontoyannis
Prof. Ralph Steinman (*Nobel prize 2011*)
Nikolas & Elizabeth Kontoyannis



The Artemis Association

The Artemis Association was established in Greece in 1994. It is a charitable organization, supporting families and fostering research on the causes of Histiocytoses. The Artemis Association is named after a little girl called Artemis who died at the age of eighteen months, suffering from multi-system Langerhans Cell Histiocytosis.

The Artemis Association comprises of doctors, parents, patients and their relatives and friends. Its objectives include supporting patients and their families, motivating and funding international research focused on identifying the pathogenesis of the condition and keeping Hospitals up to date with the latest treatments. www.histioartemis.gr



**The Histiocytosis
Research Trust**

Elizabeth Kontoyannis
Dr John Pritchard
(*Founder of the HR Trust & the Nikolas Symposium*)



The Histiocytosis Research Trust

The Histiocytosis Research Trust was set up as a registered charity in 1991 in the UK & Wales (No 1004546). It is dedicated to promoting and funding scientific research for uncovering the causes of all histiocytic diseases, which include Langerhans's Cell Histiocytosis and Haemophagocytic Lymphohistiocytosis, so as to ensure early diagnosis, effective treatment and a cure.

The Trust also 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. www.hrtrust.org

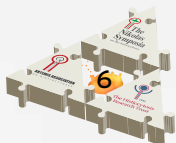
Statement of Objectives

- The promotion and furtherance of scientific research into the physiology and pathology of histiocytes and the aetiology of Histiocytoses.
- The development of more accurate means for assured diagnosis, improved protocols for management of patients and ultimately measures for prevention of Histiocytoses.
- The provision of information in support of patients and families affected by Histiocytoses.

Working Together

- In 2005, we committed £150,000 to fund 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 tumors.
- In 2009, we allocated £220,954 to fund a ground-breaking project at the Institute of Child Health at University College London. The project investigated, in a mouse model, how to introduce a normal Perforin gene –the gene most commonly affected in inherited HLH– into white blood cells. Based on the success of the methods developed during the project, Professors Bobby Gaspar and Adrian Thrasher together with Dr. Marlene Carmo, are now planning to develop this form of gene therapy to restore normal immune function in patients suffering from HLH.
- In 2012 we committed funds to a collaborative project at the Centre for Molecular and Cellular Biology of Inflammation, Kings College London & at the Institute of Cellular Medicine, Newcastle, led by Professors Frederic Geissmann and Matthew Collin. This project will build on the recent important discovery of a genetic mutation in half of LCH samples tested. This mutation (called BRAF V600E) is found in several human tumour types and alters the transmission of signals from the cell surface to the nucleus. In their project, Professors Geissmann and Collin are exploring how the mutation affects the behaviour of Langerhans cells and whether it is found in other cell types in LCH patients. This important project will cost £327,000 over three years.
- Our research programmes provide a beacon of hope for the many thousands of children and adults battling with Histiocytoses, but to ensure the research continues we need you to pledge your support..

We depend on your generosity.





1st Fundraising Event March 19th, 2009

Apostolos Kontoyannis - Prof. Peter Beverley - Prof. Robert Arceci
Simos P. Palios Honorary Trustee of the Artemis Association

Get in touch!

Your support makes a vital difference to our research goals and the patients' life.

To make a donation, please see below our bank details, or you can visit our website **www.histioartemis.gr**

National Bank of Greece: 65, Akti Miaouli, 185 36 Piraeus, GREECE

Donation in EURO: GR520 110 702 00000 7027 4402 356 - SWIFT ETHNGRAA

Donation in USD: GRO7 0110 7022 0000 7025 0342 808 - SWIFT ETHNGRAA



10 Skouze street, 185 36 Piraeus, Greece, Tel. +30 210 4520 453, Fax. +30 210 4516 990
e-mail: info@histioartemis.gr • web: www.histioartemis.gr