



## ***AN INTERNATIONAL COMMUNITY DEDICATED TO THE RESEARCH AND TREATMENT OF HISTIOCYTIC DISORDERS***

The Histiocyte Society is a nonprofit organization, comprised of an international group of more than 220 physicians and scientists, committed to improving the lives of patients with histiocytosis by conducting clinical and laboratory research into the causes and treatment of this disease.

### **Organizational Goals**

To improve the state of knowledge of the histiocytic disorders and improve the welfare of patients with these disorders;  
To promote, facilitate and carry out research in histiocytic disorders;  
To facilitate and provide a forum for health care professionals for effective communication concerning these aims;  
To promote education and to educate physicians, scientists, and others in matters related to the histiocytic disorders;  
To advise lay organizations in educational and other matters concerning the histiocytic disorders; and  
To collaborate with organizations that have common goals.

### **Background and History**

An historical international workshop in Philadelphia, initiated by Dr. Giulio D'Angio from the University of Pennsylvania Hospital, convened on May 16, 1985, and led to the foundation of the Histiocyte Society. Participants numbered fifteen at this inaugural meeting; membership has subsequently grown to approximately 220 scientists, physicians, and nurses. This international society has provided a forum for the exchange of information and a framework for organized activities of fundamental importance.

### **Accomplishments**

After extensive research and collaboration, a common language of uniform classification, standardized diagnostic criteria, and guidelines for patients' evaluation and follow-up was agreed upon and has been accepted worldwide.

In 1987, the Writing Group endorsed the use of the term "Langerhans cell histiocytosis" (LCH) to designate the various clinicopathologic conditions previously known as Hand-Schuller-Christian disease, Abt-Letterer-Siwe disease, Hashimoto-Pritzker disease, and eosinophilic granuloma of bone.

LCH was intentionally chosen to replace the name "histiocytosis X," which had been proposed in 1953, the "X" demonstrating the lack of knowledge about the etiology and pathophysiology of LCH.

"Langerhans cell histiocytosis" was agreed upon, in order to acknowledge the central role of the Langerhans cell in these diseases, and the current nomenclature reflects an increased understanding of these disorders.

Also in 1987, as a result of the collaborative efforts, a simple stratification system for practical use was introduced for LCH. The Writing Group of the Histiocyte Society recommended a division of the histiocytic disorders into three classes: Langerhans cell histiocytosis (LCH) (class I), Non-Langerhans cell histiocytosis (class II), and Malignant histiocytic disorders (class III).

A minor revision of this classification has more recently been proposed, and the three major groups are now termed: Dendritic cell-related disorders (of which LCH is by far the most common), Macrophage-related disorders, and Malignant disorders.

For the first time, it became possible to collect large enough numbers of patients diagnosed according to strict criteria and evaluated in a uniform way to carry out a randomized trial of therapy.

As a result, the LCH-I treatment protocol was launched in 1992. It then became necessary to devise a salvage therapy protocol for patients with refractory or progressive LCH, and LCH I-S was opened in 1994. The HLH-94 (hemophagocytic lymphohistio-cytosis) treatment protocol, designed primarily for the primary, inherited disease familial

hemophagocytic lymphohistiocytosis (FHL), was initiated in 1994. The results of LCH-I and the DAL-HX (Austrian-German study from 1990) studies formed the basis for the LCH II study, which opened in 1996.

In 1998, the LCH-CNS study was initiated to specifically address central nervous system LCH, as well as neurodegenerative disease. LCH-III, the third international study on Langerhans cell histiocytosis, started in April of 2001 and is based on the findings of LCH-I and LCH-II (both LCH-I and LCH-II are now closed).

These treatment protocols are recognized as the most authoritative guide to treating the histiocytic disorders and are utilized extensively by physicians and treatment centers throughout the world.

## Current Histiocyte Society Studies

- LCH-III (closed to new patients)
- HLH-2004 (Hemophagocytic Lymphohistiocytosis)
- LCH-Adult-1 (Adult LCH patients)
- LCH-CNS-2003 (Central Nervous System)
- LCH-S-2005 (Salvage)
- LCH-HCT-2006 (Reduced Intensity Hematopoietic Cell Transplantation For Patients With Resistant LCH)
- LCH-IV (to be opened in mid 2010)

## Histiocyte Society Membership

Membership is open to all those wishing to pursue the goals of the Society. Membership applications are reviewed annually for approval and require a current Society member's sponsorship. Currently, members include approximately 220 physicians, scientists, and nurses from 40 countries. For more information about joining the Histiocyte Society, download a membership application at [www.histiocytesociety.org](http://www.histiocytesociety.org) or contact the Histiocyte Society Secretariat's Office (see contact information below).

## Histiocyte Society Annual Meetings

The Histiocyte Society holds annual scientific meetings in various locations throughout the world. Proposals for research studies about histiocytosis, as well as the results of completed studies, are shared during the presentations at these meetings. The 26th Annual Meeting of the Histiocyte Society will take place in Boston, MA, USA from October 18 to 20, 2010. Visit [www.hsboston2010.org](http://www.hsboston2010.org) for more information.

### Histiocyte Society Executive Board

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St. Anna Children's Hospital- Vienna, Austria

**Sheila Weitzman, Member-at-Large**

Hospital for Sick Children- Toronto, Canada

### Histiocyte Society Working Groups

<u>Group Name</u>	<u>Chairperson</u>
Adult Histiocytosis .....	Maurizio Aricò
Epidemiology/Late Effects ....	Riccardo Haupt/Vasanta Nanduri
HLH .....	Jan-Inge Henter
LCH-III .....	Helmut Gadner
LCH-IV .....	Milen Minkov/ Carlos Rodriguez-Galindo
LCH-HCT.....	K. Scott Baker
LCH-S.....	Jean Donadieu
Rare Histiocytic Disorders .....	Ossama Abla

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