

**Development of a Multicenter International Collaborative Network for the Study of
Rare Eosinophil-Mediated Disorders
July 18, 2007
Snowbird, UT**

Summary

A 1-day workshop entitled “Development of a research network for the study of eosinophil-mediated disorders” was convened on July 18, 2007 in Snowbird, Utah, in conjunction with the biennial meeting of the International Eosinophil Society. The workshop was funded by the Office of Rare Diseases Research at the National Institutes of Health, GlaxoSmithKline, and the American Partnership for Eosinophilic Disorders. Forty-three clinicians and scientists from varied disciplines with expertise in the diagnosis, pathogenesis and treatment of eosinophilic disorders participated in the discussions. The goal of the workshop was to provide the framework for further collaborative clinical research studies of rare eosinophil-mediated diseases. To address this goal, the workshop was divided into three parts: 1) a group discussion of a consensus research definition(s) for hypereosinophilic syndrome (moderated by Hans-Uwe Simon), 2) a presentation of the steps required to form a collaborative network drawing from existing models in the United States and Europe (moderated by Michael Wechsler and Florence Roufosse) and 3) focus group discussions on 5 topics (diagnosis, eosinophil-mediated pathogenesis, organ-restricted eosinophilic disorders, mechanisms of eosinophilia and eosinophil activation and treatment) with each group tasked with identifying the most important research questions within their topic and suggesting practical multicenter approaches to address these questions. Preliminary results of a multicenter retrospective study of treatment outcomes (initiated at the previous ORD-sponsored HES workshop) were also presented by Dr. Ogbogu of the NIH.

The overwhelming conclusion of the workshop was that a multicenter clinical network is needed to collect sufficient numbers of patients and to provide a central repository of patient data and samples to address fundamental questions in the diagnosis, pathogenesis and treatment of hypereosinophilic syndromes. Although it was recognized that the definition of HES proposed in the published 2005 IES workshop summary (*J Allergy Clin Immunol* 2006 117:1292) satisfies many of the requirements for a research definition of HES, a formal consensus definition is currently being developed. Furthermore, existing multicenter data on treatment outcomes in 188 patients with HES from 11 centers (all of whom participated in the workshop) is being prepared for publication. Finally, a consortium of clinical investigators has been formed with the intention of seeking funds to establish the infrastructure necessary to conduct multicenter clinical trials.