

# 2011 International Expert Meeting Brief Summary

At the largest assembly of experts on large nevi and patients affected by them, in Tübingen, Germany, on May 6-8, over 100 people met to discuss current topics in scientific research and patient care.

There were 24 expert scientists and doctors speaking on 24 topics at this meeting sponsored by Nevus Outreach. Patient association representatives from 14 countries representing 11 different nevus organizations were present to balance scientific talk with patient concerns. "The cross-pollination was unbelievable," said Mark Beckwith, Executive Director of Nevus Outreach. "More understanding of nevus patient concerns, ideas and hopes have come out of this meeting than at any time in the past. For the founders of Nevus Outreach, it has been a dream come true, made possible by years of focused effort."

The experts presented an overview of large congenital melanocytic nevi (LCMN) and neurocutaneous melanocytosis (NCM), then more specific discussions of neurological aspects, biological bases, treatment options, and possible syndromic aspects. The patients met separately and proceeded nearly unanimously with two important initiatives: the first for a global LCMN/NCM registry, asking the experts to create a working group to standardize the data to be gathered, and a second for a global LCMN/NCM patient information website.

The registry initiative is expected to take 18 months to create, with Dr. Veronica Kinsler leading a working group of 14 scientists and doctors. Dr. Harper Price has been appointed Deputy Director of this group.

With this new registry as the centerpiece, the patient associations have already begun working together to build the patient information website, serving as a multilingual clearing-house not just for the new registry, but for information on LCMN/NCM and links to each separate patient association's website, so any patient surfing the web may contact someone close to home. The goal is to build a global community to unite thousands of people who share experience with LCMN and NCM.

Without the support of the members of Nevus Outreach, the Morgan Family Foundation, the NIH and the University of Tübingen, this meeting would not have been possible.

For more in-depth information, please read [2011 International Expert Meeting for Large Congenital Melanocytic Nevi and Neurocutaneous Melanocytosis Resounding Success](#) by [Pat McAdams](#).

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