

# ALS Hope Foundation Encourages Research Collaboration



The ALS Hope Foundation believes that progress is quickest when researchers are able to work together and share ideas. The Foundation has encouraged collaborations across Institutions by supporting multi-center clinical trials and research planning meetings that involve a consortium of investigators. To date, the ALS Hope Foundation has invested in promoting collaborations by:

- ◆ Funding an exploratory meeting in May, 2001 of investigators from the University of Kentucky, Drexel University, Columbia University, University of Wisconsin, and others to plan a study that will evaluate the benefits of optimizing nutrition and NIPPV (assisted respiration) on survival and quality of life in ALS. This meeting led to the submission of the NIH grant proposal “**Early Treatment of ALS with Nutrition and Non-invasive Positive Pressure Ventilation,**” which NIH funded in 2005. It is now ongoing with the collaboration of 10 University Centers across the country.
- ◆ Providing supplemental funds to Dr. Jeremy Shefner, SUNY Upstate Medical University, for the project “**Clinical Trial of Creatine in ALS,**” initially funded by the MDA. Participants included multiple ALS Centers from the Northeast ALS Consortium (NEALS). The results were published in *Neurology*, Vol 63, 2004.
- ◆ Supporting the Investigators’ meeting for ALS Centers participating in the trial “**Use of Celebrex in ALS**”. The data from the trial were evaluated at this meeting and further strategies planned. The results were published in *Annals of Neurology*, 60:22-31, 2006.
- ◆ Supporting the annual meeting of Investigators belonging to the **NEALS Consortium**, starting in 2003 and offering yearly support to the present day. Thanks to the help of the ALS Hope Foundation, NEALS has grown from 20 centers to 35 ALS Centers, and has become a major source of new ideas for finding a cure for ALS. These meetings have resulted in NIH-funded clinical trials of the drugs **Ceftriaxone**, **Talampanel**, and **Keppra** in ALS, as well as studies to determine the **metabolic profile** and the **effects of exercise** on ALS patients.
- ◆ Providing supplemental funds to expand the NIH-funded study of **nutrition and NIPPV**, and provide respiratory equipment for those centers involved in the study.
- ◆ Supporting the inaugural meeting establishing the **Pennsylvania ALS Research Consortium** on October 25, 2006. This program will develop mechanisms to allow extensive collaboration between ALS Research Centers at Drexel University College of Medicine, the Penn State Hershey Medical Center, and the University of Pittsburgh School of Medicine. The consortium is developing a standard set of demographic and clinical information and biological samples to be collected from patients across all three centers, which will be placed in a shared database. The long term goal is to develop collaborative research projects that will be carried out across all three centers to accelerate the collection of information.
- ◆ Supporting the first investigators’ meeting to launch a **National ALS Research Group on Genetic Modifiers**. This meeting will join together investigators from across North America to collaborate on finding the genes in ALS mice that modify the severity of ALS in the SOD1 mouse model. Upon discovering what slows down the disease in mice, the group will then look for the same genes in humans and develop therapeutics that take advantage of these natural pathways.