

Research Funds at the ALS Hope Foundation and the projects they support



Carol Fox Kochenbach Research Fund

Genetic and Gender Modifiers of ALS in the mouse model
Clinical research at the MDA/ALS Center of Hope

Kevin O'Donnell Independent Living Initiative

Assistive Technology development
Adapted hospital rooms for people with ALS

Steven & Gwenn Rubin Research Fund

National ALS Research Group on Genetic Modifiers

Sharon Balick Fund

PA ALS Research Consortium
National ALS Research Group on Genetic Modifiers
Translational Research Program (Inflammation in ALS)
Assistive Technology Program of the Independent Living Initiative

Janet Steen Memorial Pre-Doctoral Fellowships

Undergraduate and Student Summer Fellowships

Bo LeBoutillier Research Fellowship

Post-graduate Research Fellowships in ALS

Harold B. Furman Memorial Research Fund

Basic Research

Milton Sobel Fund

Basic Research

Sharon Balick Research Fund

The Sharon Balick Research Fund was established in her honor through the generosity of Harvey Gitlin, Phyllis Gitlin and many of Sharon's other family members and friends. The purpose of the fund is to support research that will improve the lives of people with ALS while searching for a cure. The research program includes:

The development of the brain wave-based brain-computer interface (BCI) for home and clinic use as a major part of the Kevin O'Donnell Independent Living Initiative.

The development of the Pennsylvania Consortium of ALS Centers. This project has already been initiated and will link ALS Centers in Pennsylvania (Penn State Hershey, Univ. of Pittsburgh and the Center of Hope at Drexel) in joint projects. As a first step, the centers have agreed to collect the same information and assessments across the three clinics. The program will also develop a common database, accessible through the ALS Hope Foundation web site, where information can be shared about each centers' patient population and available patient samples (blood, urine, CSF, etc.) to be used for research. Future plans include an epidemiologic study of risk factors for ALS development across the state.

The development of a Mouse Genetics Consortium. We have assembled a group of investigators interested in studying genes that modify the severity of ALS in the mouse model. It includes investigators from Johns Hopkins Univ., The Jackson Laboratory (Maine), and Univ. of Denver. A working conference is planned in February to share data and design the studies that we plan so that we can find disease modifiers in the transgenic mouse model of ALS.

The development of the Translational Research Program. This is the program at the Center that brings findings in the laboratory to people living with ALS. For instance, we are studying inflammation in ALS and have found that sPLA2 is elevated in animals and people with ALS. sPLA2 is a protein that starts up inflammation in the nerve cell and can lead to molecules that cause the cell to die. We have another small peptide called CHEC 9 that decreases the activity of sPLA2 and will be giving it to the mice that have ALS. If the mice are helped by the CHEC 9, we will bring the molecule to people. To do that we will need to do toxicology and safety testing. This is translational research and there are several similar projects that we are doing.

Carol Fox Kochenbach Research Fund

The Carol Fox Kochenbach (CFK) fund was established through the generosity and dedication of Carol and John Kochenbach along with their friends and family. The “Kochenbach Committee” has worked tirelessly year after year to raise money for research into the cause of ALS. Sadly, Carol lost her battle with ALS, but her devoted and committed friends and family remain dedicated to the cause. This fund has supported:

Studies of modifying genes in the transgenic mouse model of ALS. This project has been a long term study that is examining what genes (and proteins) can cause less or more severe ALS in the mouse model of ALS that carries the mutated gene (SOD1) responsible for 20% of familial ALS. These proteins/genes may provide targets for treatment in people with ALS and will help us to better understand motor nerve biology and the mechanisms of disease.

Support from the CFK fund enabled the laboratory to accumulate enough data to successfully apply to MDA for funding to continue the work. Now, this project has grown and has led to the development of a consortium of researchers across the United States to pool resources, data, and ideas. The consortium will be going to MDA and to NIH to keep the research going.

Inflammation in ALS in humans. This project is examining the levels of a protein sPLA2 that mediates inflammation in people with ALS and controls. We have found an increase in the levels of sPLA2 in urine from people with ALS and the mouse model. These findings have led to a clinical trial of an inhibitor of sPLA2 in the animal model in our basic laboratory. Inflammatory byproducts are also being investigated as possible biomarkers for onset and progression of ALS.

Clinical research. Progress in clinical research is speeded up when a team of experienced, talented professionals in ALS care is assembled and retained. Many clinical studies, even some clinical trials, do not receive funding, either from NIH or from pharmaceutical companies. The CFK Fund keeps our clinic team together and working on a variety of projects that serve to better characterize the disease process and allows them to take chances on trying therapeutics that may otherwise not be tested.