

Early years of ALSRG

In June 2003, in honor of the centennial birthday of Lou Gehrig, the Eleanor and Lou Gehrig MDA/ALS Research Center held an International Symposium on Clinical Trials in ALS. One of the major items on the agenda for this symposium was to establish a research group for ALS. This group would be independent of the existing ALS study groups that primarily focused on clinical trials. Rather, such a group would find common goals in improving general patient care, research and education in ALS throughout North America. Following this symposium, a memorial issue was published as a Supplement in 2004 in the ALS Journal and, at the same time, there was informal but very active discussion among investigators, which continued well after this symposium ended.

Shortly thereafter, an ALS Research Group (ALSRG) was established; at the same time, by-laws and several committees were also developed. I was elected as the first chair of the ALS Research Group (Jeremy Shefner was an elected Vice Chair) and our Website was established by Eric Sorenson. The main goal of the ALS Research Group (ALSRG) was to facilitate clinical trials (not run clinical trials), to promote other (non-pharmacological) patient-oriented research activity, and to educate all health care professionals, including young ALS doctors.

Around that time, an RFA was issued by NIH to establish a DNA repository for neurodegenerative diseases in conjunction with all of the active NIH grants. We quickly realized that this was such an important endeavor. A meeting to initiate a DNA repository for ALS was held in Chicago. People were energized to initiate this important project. Realizing the RFA fund was not sufficient to carry out the task, I negotiated with MDA and ALS Association; they also joined the effort with NINDS, supporting existing grants at that time (Mino study, CoQ10 study, Nutrition/Pulmonary study, and a Ceftriaxone trial).

Simultaneously, there was also a highly active effort to develop a common ALS Database from ALSRG. One meeting was organized by ALS Association in Boston. This effort was also beneficial for the DNA repository because a special committee worked to develop a data dictionary and a minimum dataset, both of which were most helpful to set the database for the ALS DNA repository. We also made a creative arrangement to fund all of the existing 70 plus ALS Centers, regardless of the limited NIH funding. This RFA was, regrettably, short in duration due to budget constraint at NIH; nevertheless, in this short period (approximately one year), the ALSRG collected a large number of DNA from the patients and healthy controls (~ 1857 ALS DNAs and 1578 control DNAs). It was good to know that major ALS stakeholders (NIH, MDA, and ALS Association) partnered in order to participate in this important project. Subsequently, the paper was published (Gwinn K, Corriveau RA, Mitsumoto H, et al. Amyotrophic Lateral Sclerosis: An Emerging Era of Collaborative Gene Discovery. PLoS ONE 2007;1:e1254).