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ABSTRACT FORM

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Background: The Agency for Toxic Substances and Disease Registry (ATSDR) launched the congressionally mandated National ALS Registry (Registry) in 2010 to identify ALS cases in the United States. To enhance the Registry, ATSDR conducted a four-year pilot study to determine the feasibility of developing a biorepository linked to the Registry. The results indicated that a biorepository was feasible and in January 2017 the National ALS Biorepository (Biorepository) was launched.

Objective: Develop a geographically diverse biorepository to help advance ALS research.

Methods: Participants must have enrolled in the Registry and consented to be contacted about research projects or receive information about the Biorepository. Participants can contribute to one or both components: 1) in-home collection of blood, urine and/or saliva; and 2) postmortem collection of brain, spinal cord, CSF, bone, muscle, and skin. Blood and urine specimens were processed into smaller aliquots and DNA and RNA are extracted. Brain and spinal cord were processed into fixed and frozen sections.

Results: Three hundred and thirty-nine people consented to donate biological specimens during the pilot study from all 50 states and 330 provided specimens at least once. Participants’ ages ranged from 31 to 87 years and 60% were male. Fifty-four percent of participants lived 50 or more miles from an ALS specialty/referral center. Thirty people consented to postmortem tissue donation from 18 states, aged 43 to 75 years at consent and 50% male. Twenty-one postmortem donations have been completed. The first 20 cases examined showed neuropathological-confirmed ALS with TDP-43 inclusions (ALS-TDP) with a mean age at death of 63 years (range: 43-76), 40% male, and mean brain weight of 1269g. Sixty-five percent of subjects had co-morbid pathological diseases, including the neuropathological changes of Alzheimer disease, primary age-related tauopathy, Lewy body disease, vascular disease with infarcts, encephalitis, and tumor. The Biorepository launched in 2017. Approximately 200 ALS patients enrolled in the Registry have consented to provide blood, urine, and/or saliva specimens and 20 have consented to postmortem tissue collection.

Discussion/Conclusions: Creating a geographically diverse biorepository has unique challenges. These specimens will be a valuable resource for researchers who want to request specimens for ALS studies.