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The Ethics of Genetic-Research on Indigenous Populations

In this paper I will focus on an ongoing research project to study a high incident of cases of Lytico-Bodig (ALS, or Lou Gehrig's disease) and PDC (Parkinson-Dementia Complex) amongst the indigenous people known as Chamorros on Guam and the Northern Marianas Islands. Research involves removing the brains of deceased elderly Chamorro individuals who are either afflicted or healthy soon after death on Guam and then sending the samples to Mount Sinai Medical Center in New York and the University of Pennsylvania where they are stored and can be shared globally with other researchers interested in this area of study. Serving as a case study, I will examine the structure and protocols of this Chamorro-based research project in light of several more recent improved efforts to formulate ethical and procedural guidelines for research with human subjects and in particular indigenous communities. This will allow us to not only evaluate the specific study in question, but review over the adequacy of these new efforts to protect native people who serve as research participants in these sorts of studies.