

## **RESOURCE SHARING POLICY**

**NOTICES WILL BE POSTED ON THE TARCC WEBSITE DESCRIBING TARCC RESEARCH AND RESOURCES AND THE MEANS FOR ACCESSING THESE RESOURCES.**

**Patient Confidentiality:** All data collected through the Texas Alzheimer's Research and Care Consortium (TARCC) is de-identified at individual sites prior to shipment to the Database Coordinating Center (DCC) at UTSW. Any additional potentially identifying information (based on the requested information and nature of the protocol) will be removed by DCC personnel prior to transfer. No data that enable identification of individual patients will be shared or otherwise distributed under any circumstances.

**Data Requests:** All data requests will be considered and approved solely by the TARCC Steering Committee, which will determine access to all data and resources developed through TARCC efforts.

**Data Presentation:** Beyond publication of results in peer-reviewed journals and presentations at national meetings, summary results for the study cohort will be posted on the TARCC website: (<http://www.txalzresearch.org/>). In addition, the TARCC website will describe procedures for requesting data.

**Tissue Samples:** All residual DNA and tissue samples collected through the TARCC will be catalogued and stored for future study. The TARCC will make available residual DNA, SNP resources, and other samples to investigators upon request, subject to approval by the TARCC Steering Committee.

**GWAS Data:** Raw GWAS and accompanying phenotypic data, as approved by the TARCC Steering Committee, will be shared with investigators in support of meta-analyses of Alzheimer's genetics.

**Patient Identification and Referral for Research Studies:** Any direct contact of TARCC patients by outside investigators is strictly prohibited. However, TARCC will make information on non-TARCC studies available to patients upon formal request, subject to approval by the TARCC Steering Committee.

**Acknowledgments:** All publications and presentations utilizing TARCC data will acknowledge TARCC support as listed in the TARCC Acknowledgement Policy.