

## **SCHEDULE 1 – Clinical Research in ALS and Related Disorders for Therapeutic Development Consortium**

### **Clinical Research in ALS and Related Disorders for Therapeutic Development Consortium (CReATe) Dataset Publication Policy**

The **C**linical **R**esearch in **A**LS and Related Disorders for **T**herapeutic Development (CReATe) Consortium is a Rare Diseases Clinical Research Consortium (RDCRC) that is part of the National Institutes of Health (NIH) Rare Diseases Clinical Research Network (RDCRN). The CReATe Consortium has multiple ongoing protocols, through some of which whole genome sequencing (WGS) data are generated alongside clinical (phenotypic) data. These WGS data have been generated through a partnership between CReATe and St. Jude Children’s Research Hospital (SJCRH), with the principal goals of identifying genetic/genomic contributions to disease and genetic/genomic modifiers or determinants of phenotype.

The CReATe Data Access Committee anticipates that the data generated through the CReATe Consortium’s activities will be useful to other researchers (scientists who are employed by, or a student enrolled at, or legitimately affiliated with, an academic, non-profit, or government institution) who may wish to develop new analytical methods, validate results, or identify additional genetic variations in the data.

Investigators who use data generated by the CReATe Consortium must appropriately acknowledge CReATe and SJCRH as the source of these data in presentations and publications, using the following wording, “This study makes use of data generated by the Clinical Research in ALS and Related Disorders for Therapeutic Development (CReATe) Dataset of St. Jude Children’s Research Hospital and the CReATe Consortium” and reference <https://doi.org/10.1186/s40035-025-00516-2>

**Users should note that the CReATe Data Access Committee bears no responsibility for the further analysis or interpretation of these data, over and above that published through CReATe/SJCRH.**