



When displaying data from the ARTFL/LEFFTDS/ALLFTD/4RTNI studies, please follow these guidelines:

- Present all data so that no participant or family member could assume s/he is represented as an individual or by an individual data point. Regardless of whether it is actually possible for a participant to draw such a conclusion with certainty, data should be displayed in a manner so that participants would not be led to make assumptions about their own data.
- Descriptions of the datasets should be sufficiently vague to maintain confidentiality. Absolutes in reference to the timing and content of the datasets should be avoided. For example, state “ARTFL/LEFFTDS data that were deemed useable, approved by study management, and passed all quality control measures were included in these analyses.”
- Pay careful attention to all information relating to mutation status. This data is only provided by request.
- In all descriptions and depictions of these data, use extreme care with regard to ages, ages at onset, and age ranges.
- Strongly consider avoiding scatter plots. If a scatter plot is used, individual ages, ages at onset, estimated/parental ages at onset, and age ranges should be omitted from the x-axis.
- Displaying extreme values in isolation from other data should be avoided.
- Geographic information as it relates to participant data (including any portion of participant zip codes) should not be referenced in publications or displayed with data. This information is omitted from datasets provided by the ALLFTD data management team.
- Use extreme discretion when including any dates (including dates of data freezes).
- Ns of 1 should be avoided. At a minimum, cells should contain at least 3 individuals.
- If presenting pedigree data in conjunction with ARTFL/LEFFTDS/ALLFTD/4RTNI data, avoid displaying the data in any way that participants and/or pedigree members could learn or make assumptions about information about their mutations or who is affected in their families. An example of an acceptable pedigree is shown.

