

## When displaying data from ARTFL/LEFFTDS, 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 ARTFL/LEFFTDS 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 ARTFL/LEFFTDS data. This information is omitted from datasets provided by the ARTFL/LEFFTDS 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 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.

