ALS Genetics Discussion Guide

FAMILY HISTORY

Person with ALS

Positive “Familial” ALS

Negative or Unknown “Singleton”

GENETIC TESTING

Positive

Negative or Uncertain

WHAT IT MEANS

FAMILIAL, GENE IDENTIFIED
There is a family history of ALS and genetic testing was positive. Family members have an increased chance for ALS.

FAMILIAL, NO GENE YET IDENTIFIED
There is a family history of ALS, and genetic testing was negative, uncertain or not done. Family members usually have an increased chance for ALS.

SINGLETON, GENE IDENTIFIED
There is no known family history of ALS, but genetic testing was positive. Family members have an increased chance for ALS.

SINGLETON, NO GENE YET IDENTIFIED
There is no family history of ALS and genetic testing was negative, uncertain, or not done. Family members usually have a low chance for ALS.

Genetic testing may consist of testing for a single gene (i.e. C9orf72) or multiple genes. These are general guidelines and it is important to review your family history and test results with a genetic counselor or neurologist.