You're Not Alone:
Support For Families Facing Genetic FTD

People with genetic FTD in their family experience a wide range of complex emotions. Genetic peer support groups provide a welcoming, safe and confidential space to connect with others facing similar uncertainties.

Members feel less isolated by sharing their experiences, learning from one another, and exploring practical strategies for coping with genetic risk and the uncertainty it may bring.

Most importantly, these groups help people build a supportive community with people who understand what it means to have genetic FTD in the family.

Genetic support groups are for people who do not have FTD symptoms and know the specific FTD-causing gene that runs in their family.

NEW Genetic Risk FTD-ALS:

For people who know the gene in their family can cause FTD and ALS. Members may or may not have had predictive genetic testing. This group provides support and connection for people navigating the additional uncertainty of developing FTD, or ALS, or both.

(Genes associated with both FTD and ALS: *C9orf72, VCP, TARDBP, SQSTM1, DCTN1, CHCHD10, CHMP2B, TBK1, TIA1, CCNF, OPTN, FUS)*

Familial FTD:

For people with a biological relative with a confirmed genetic form of FTD. This group is open to people who are undecided about testing or have chosen not to undergo predictive testing.

Persons at Genetic Risk:

For people who have undergone predictive genetic testing and received a positive result. The group offers a supportive space to connect with others who understand the emotional complexity, uncertainty, and life considerations involved in living with a confirmed genetic risk for FTD.





If interested, contact the AFTD HelpLine at 1.866.507.7222 or info@theaftd.org.