



The Association for  
Frontotemporal Degeneration  
Opening the gateway to help and a cure

# The Genetics of FTD: Should you worry?

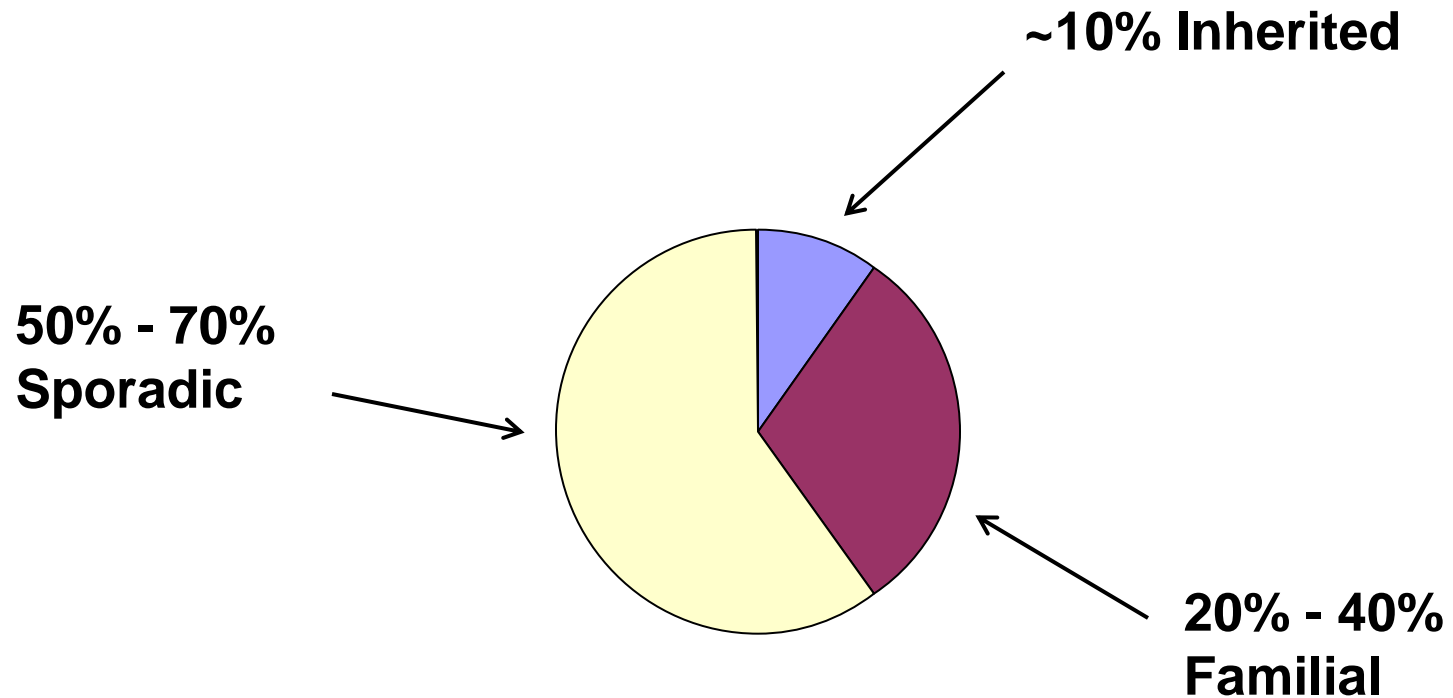
Cambridge, MA June 2011

# The Genetics of FTD

## Goals:



- Broad strokes of FTD inheritance
- Overall picture, vocabulary
- Equip you with the fundamental questions, understanding and resources to pursue the answer for your family.

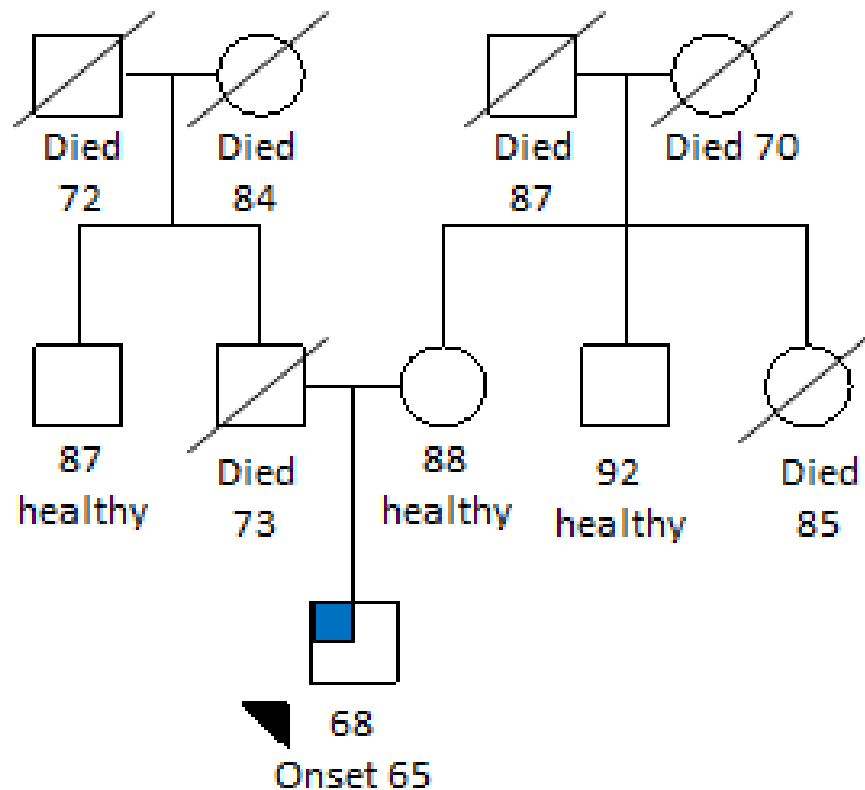
# Genetics of FTD



# Sporadic

## Legend

-  FTD
-  Deceased

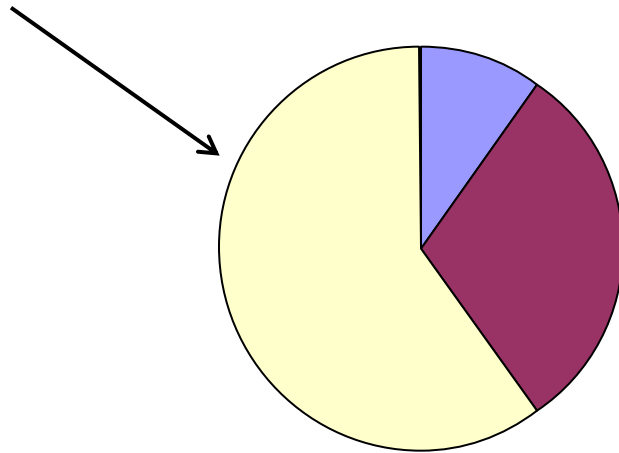


# Genetics of FTD

**50% - 70%  
Sporadic**

Not inherited

Family members  
have general  
population risk



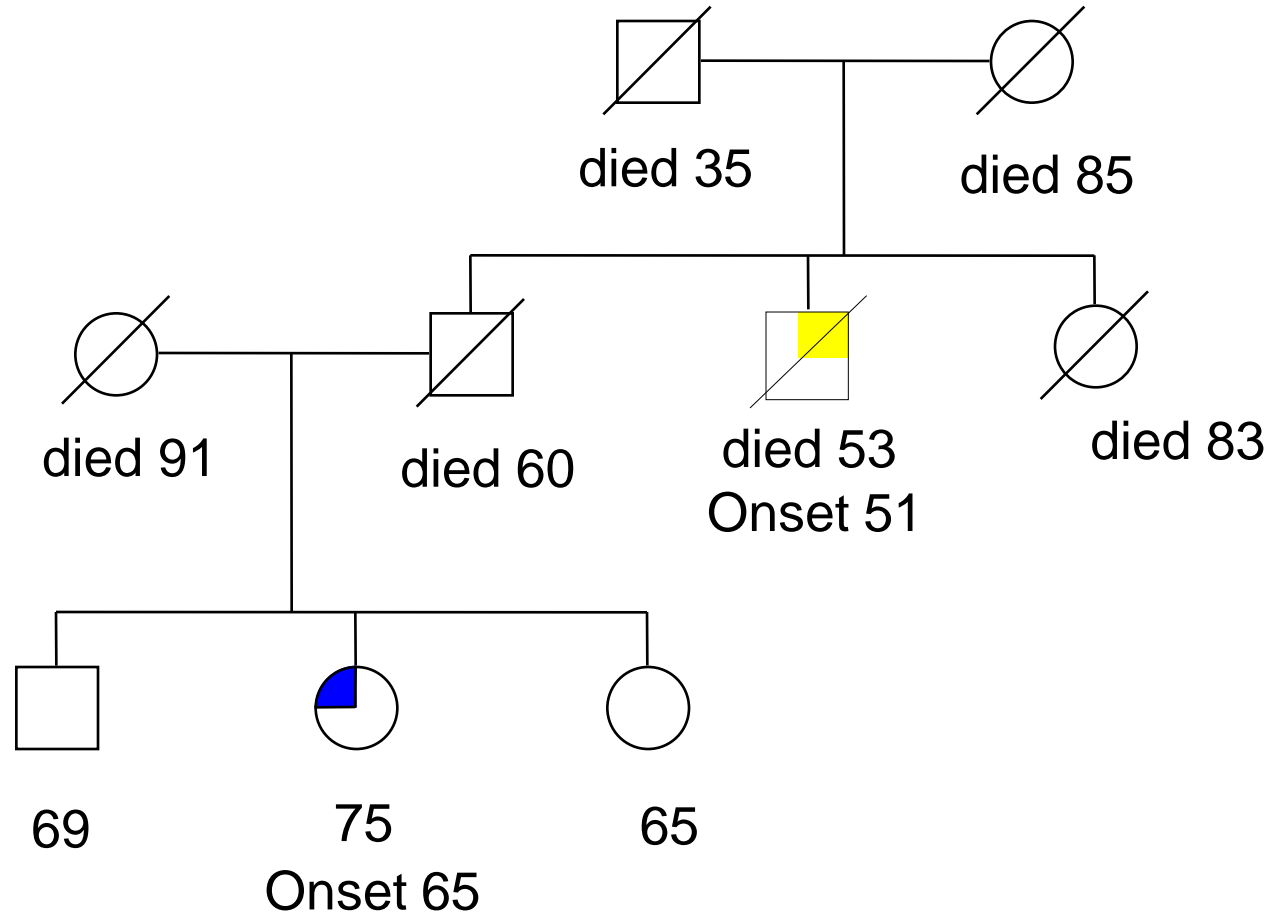
# Familial Pattern?

## Legend

 FTD

 Deceased

 ALS



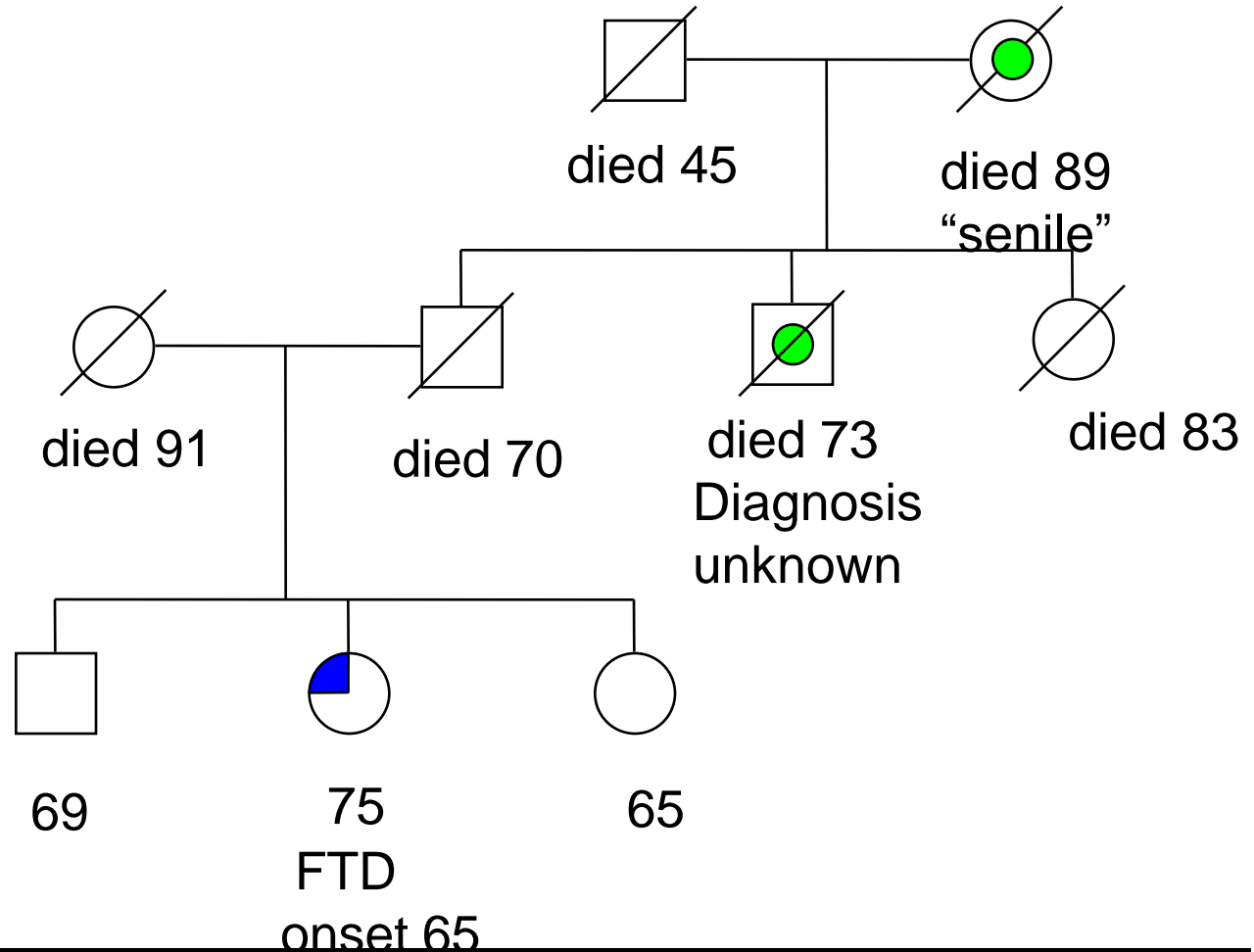
# Familial Pattern

## Legend

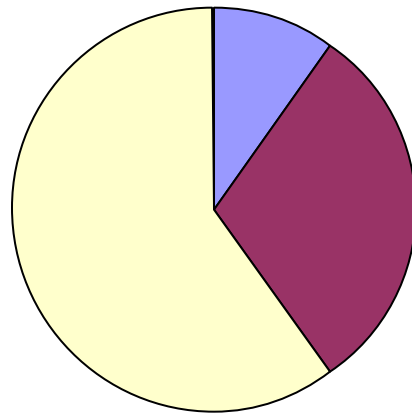
 FTD

 Deceased

 Dementia



# Genetics of FTD



**20% - 40%  
Familial**

May be inherited

Family members are  
at increased, though  
undetermined, risk



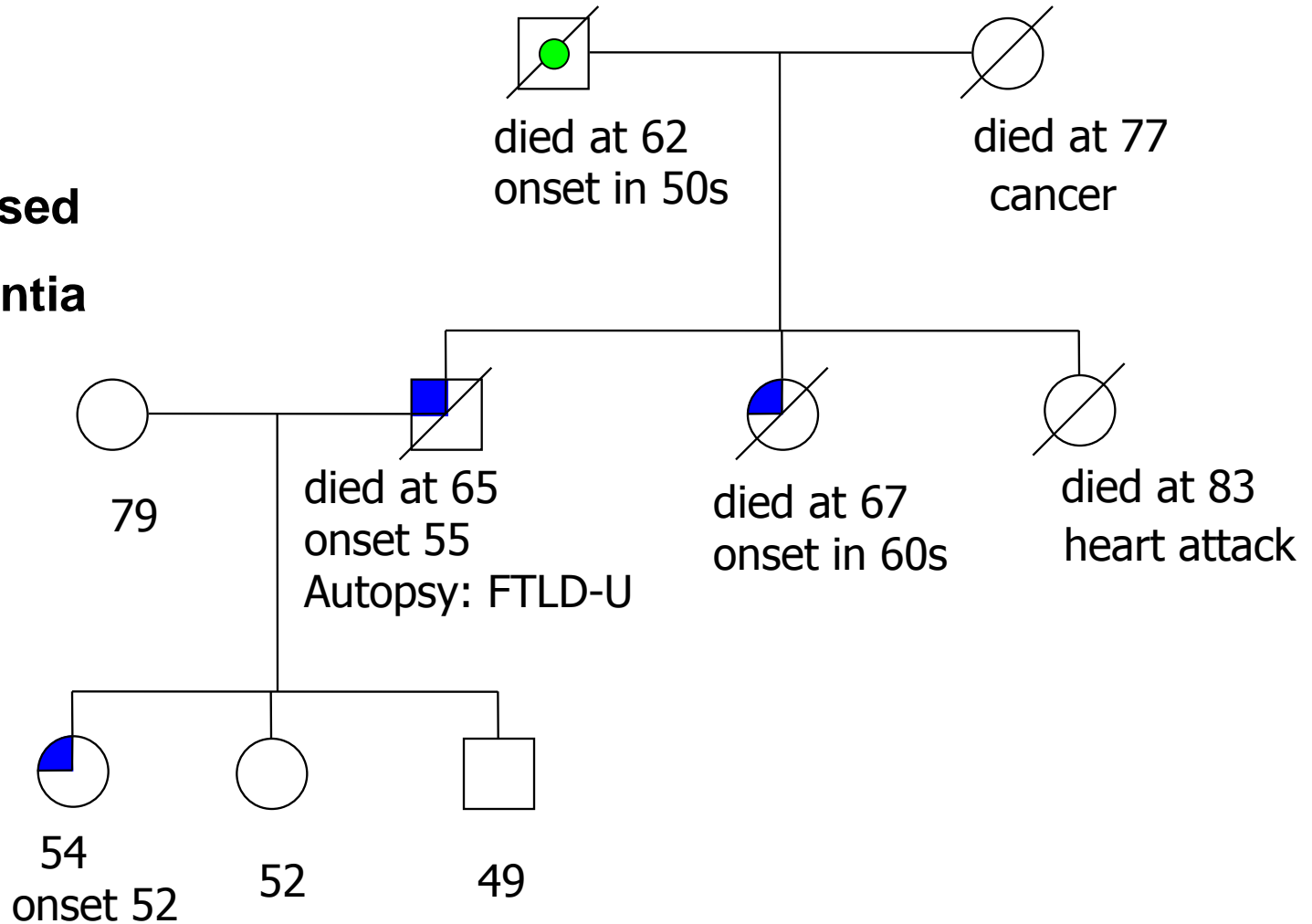
# Autosomal Dominant Inheritance

## Legend

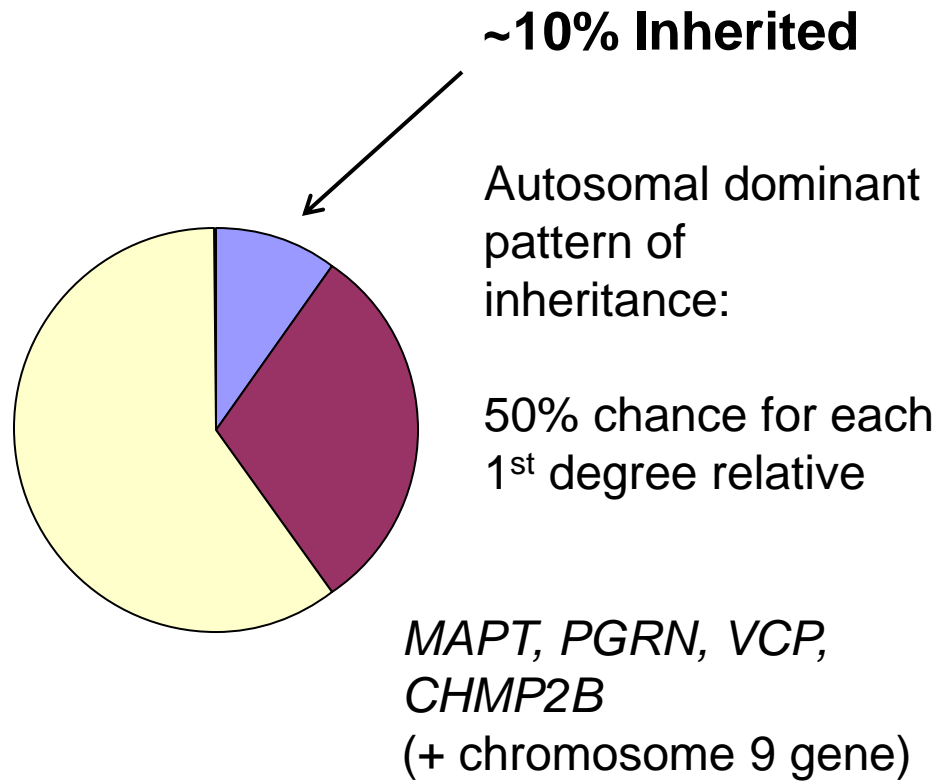
 FTD

 Deceased

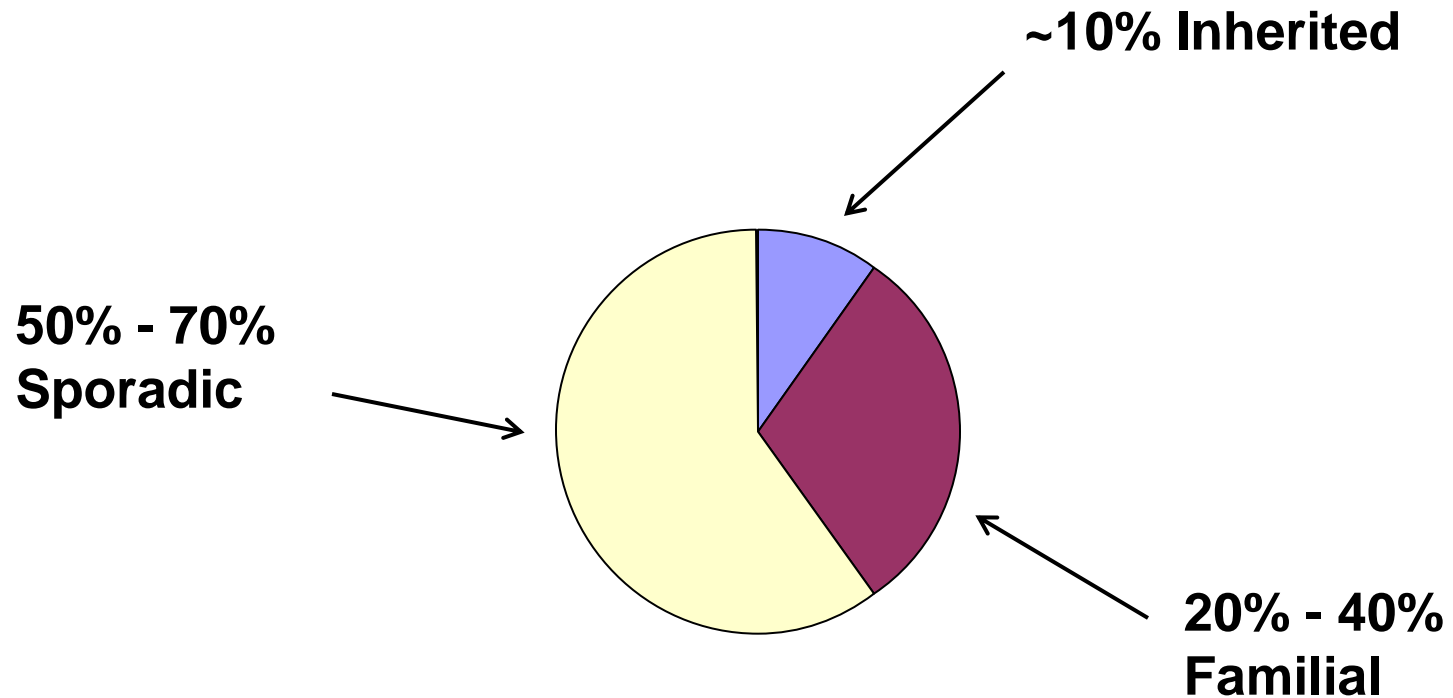
 Dementia



# Genetics of FTD



# Genetics of FTD



# Genetic Testing

- Must begin with a person who has the disease
- If a mutation is found in the diagnosed person, testing will be informative in family members
- Research testing: No cost, no results to you. Motivation is to advance knowledge for future generations
- Clinical testing: You pay for, you get the results.

# Genetic Counseling

- Construction of a family history and analysis for pattern of inheritance and genetic risk
- Collection of medical records to confirm/clarify family history
- Education about natural history of FTD in your family and discussion of recurrence risk
- Discussion of benefits and limitations of genetic testing
  - Must give informed consent to get testing
  - Family members will view things differently

# [www.theaftd.org](http://www.theaftd.org)

**To find a clinical team with experience in FTD:**

<http://www.theaftd.org/support-resources/us-regions>

**To find a genetic counselor with experience in adult neurogenetics:**

[www.nsgc.org](http://www.nsgc.org)

**For information on collecting family medical history:**

[www.hhs.gov/familyhistory](http://www.hhs.gov/familyhistory)