

Sharing Your Experiences to Advance FTD Science: Getting Involved with Research

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2014-2019



Washington University in St. Louis

SCHOOL OF MEDICINE

KnightADRC
Alzheimer's Disease Research Center

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LEFFTDS – The Ask



Participants

- From *MAPT*, *GRN*, or *C9orf72* FTD families
 - Mutation carriers with FTLD spectrum symptoms
 - Mutation carriers with no symptoms
 - Non-mutation carriers with no symptoms

Each visit

- Clinical (functional, lifestyle, neuropsychological) measures
- MRI
- Blood measures
- Spinal fluid (CSF) measures

The Next 5+ Years: 2019-2025



<https://www.allftd.org/>



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ALLFTD Encompasses ARTFL & LEFFTDS

26
Clinical Sites

4048
Visits

2412
Participants

3130
UDS visits in
NACC's database

2739
Visits with
associated MRI's

3696
Visits with
associated blood
samples

1020
Visits with
associated CSF

1847
Participants
with research
genotyping



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Rural Urban Commuting Area (RUCA) Code

Urbanized Area					Rural Area				
1	2	3	4	5	6	7	8	9	10
(80.7%)	(6.5%)	(0.6%)	(5.8%)	(0.7%)	(0.2%)	(2.9%)	(0.2%)	(0.0%)	(2.4%)

RUCA Code Groupings: Population Size & Commuting Flows to Urbanized Area or Urban Cluster

Rural:	10	
Small Town:	7,8,9	2.5K to 10K
Micropolitan:	4,5,6	10K to 50K
Metropolitan:	1,2,3	



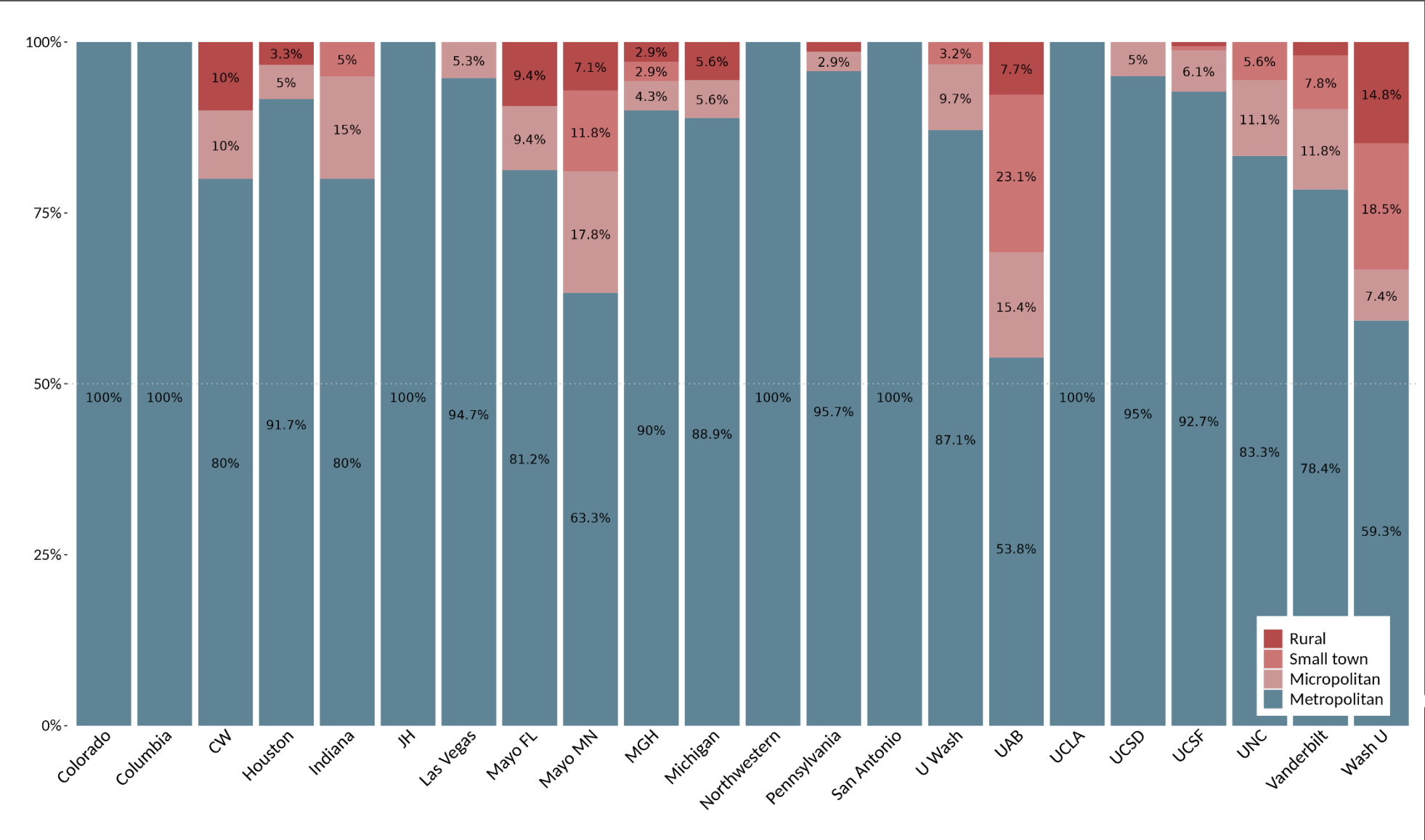
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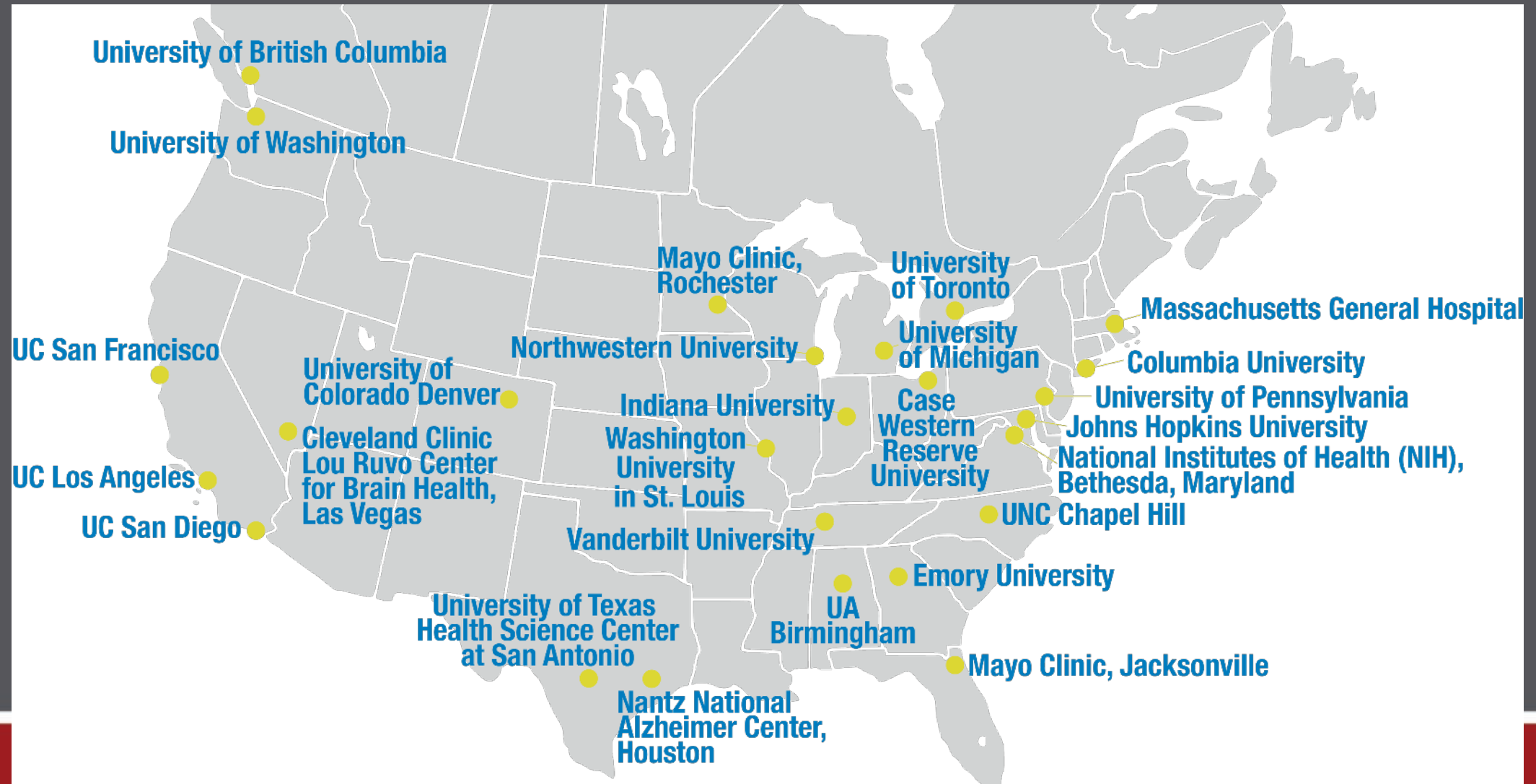
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Site Analysis of RUCA Codes



RUCA Code Groupings:
Rural: 10
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ALLFTD Consortium – Site Map



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