



The Association for  
Frontotemporal Degeneration  
**FIND HELP • SHARE HOPE**

# FTD ADVOCACY, EDUCATION AND SUPPORT

**ADC – ORE Core Fall Meeting**

Sharon S. Denny, Program Director, AFTD | October 19, 2018

# Help & Hope

AFTD works to bring help for those affected today – and to bring hope for a future without this disease.

Support | Education | Research | Advocacy | Awareness

# The Experience of FTD

## Less common dementia

- Affects estimated 50,000-60,000 in U.S. <sup>1</sup>
- No treatments to slow or stop progression

<sup>1</sup> Knopman, D., Roberts, O. (2011); CurePSP



# The Experience of FTD

## Poorly understood symptoms

- Behavior, language or motor symptoms; not memory
- Avg 3.6 years to diagnosis<sup>1</sup>
- Primary impact on “social brain” – alters social contract

<sup>1</sup> Diehl & Kurz 2002; Zanto & Gassally, 2013

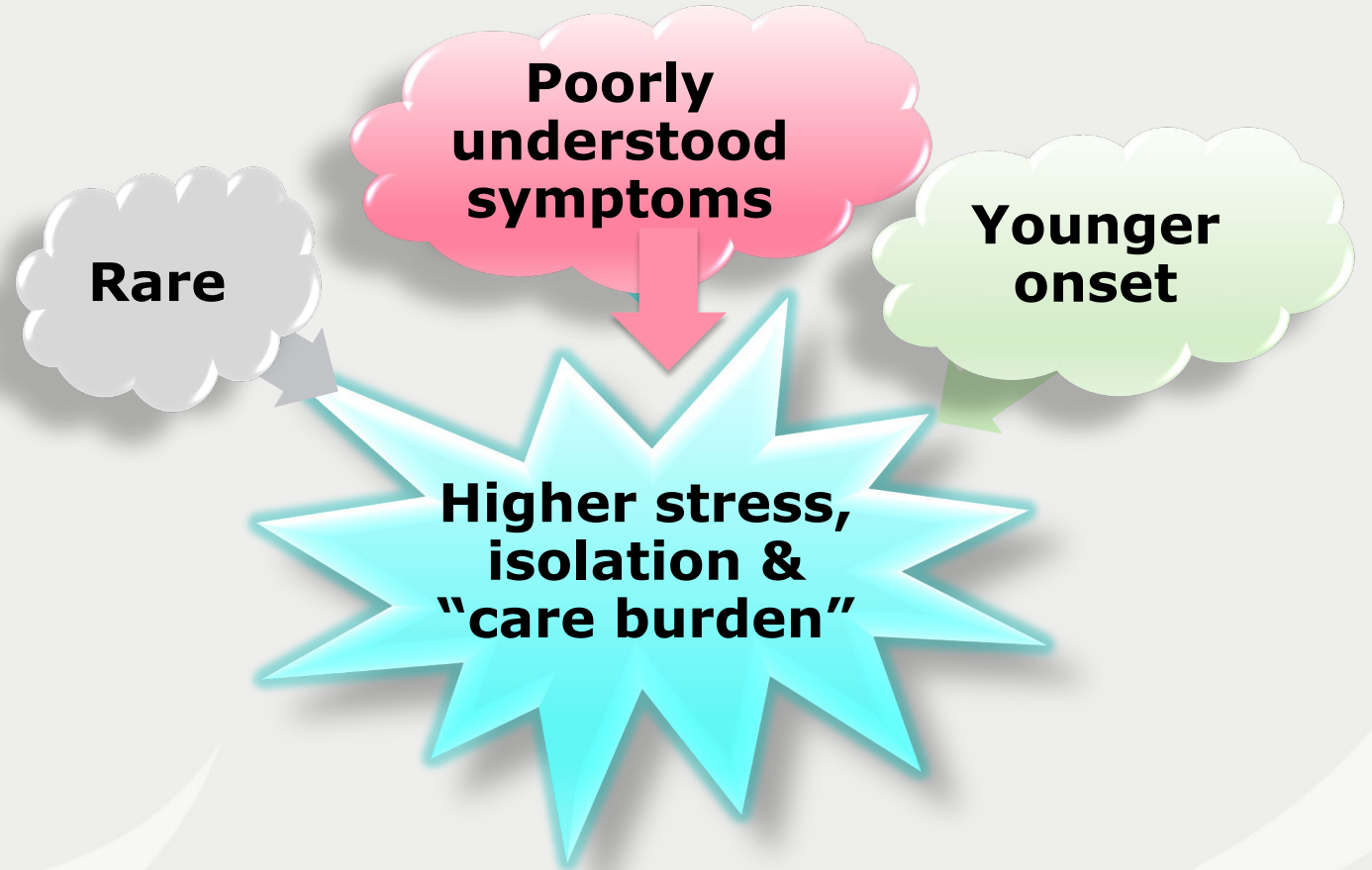
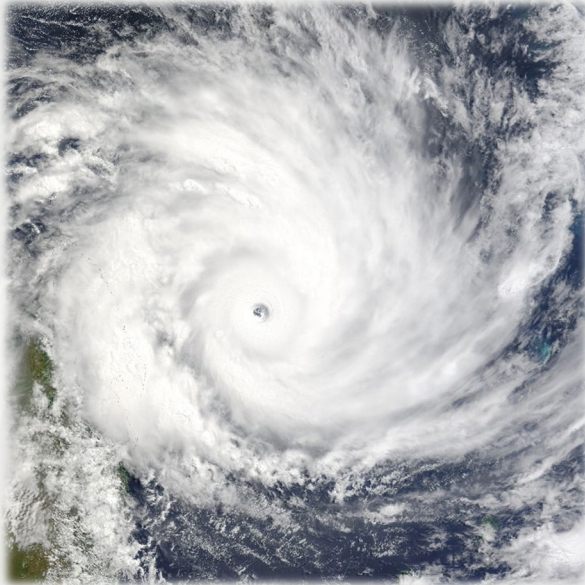
# The Experience of FTD

## Most common dementia under age 60

- Employed, often peak of career
- Physically robust and active
- Family dynamics
- Financial impact



# The Experience of FTD



# Impact on the family system

- Coping long before diagnosed
- Symptoms not recognized as illness
- Role changes (loss of employment; child/young adult caregivers, household tasks)
- Behaviors intrusive, embarrassing
- Financial and legal issues
- Isolation magnifies challenges

# Care & Support

## **Alzheimer's approaches are not sufficient**

- Eligibility issues under 65
- AD meds not indicated
- Falls to families to educate, advocate & provide care

## **Need**

- Peer support and FTD education
- Individualized beh. & environ. strategies
- Creative problem-solving



SYMPTOMS		POSSIBLE SIGNS
<p><b>Disinhibition</b></p> <p>A loss or lack of restraint based on social norms, leading to inappropriate behavior and impulsivity.</p>	<ul style="list-style-type: none"> <li>• Making uncharacteristic rude or offensive comments</li> <li>• Ignoring other people's personal space</li> <li>• Shoplifting, reckless spending</li> <li>• Touching strangers or inappropriate sexual behavior</li> <li>• Aggressive outbursts</li> </ul>	
<p><b>Apathy</b></p> <p>Indifference or lack of interest in previously meaningful activities.</p>	<ul style="list-style-type: none"> <li>• Loss of interest in work, hobbies, and personal relationships</li> <li>• Neglect of personal hygiene</li> <li>• Loss of initiative</li> </ul>	
<p><b>Emotional blunting</b></p> <p>Loss of warmth, empathy, or concern for others.</p>	<ul style="list-style-type: none"> <li>• Indifference to important events (e.g., death of a family member or friend).</li> <li>• Failure to recognize that loved ones are upset or unhappy</li> </ul>	
<p><b>Compulsive or ritualistic behaviors</b></p> <p>Single behaviors or routines that are performed over and over.</p>	<ul style="list-style-type: none"> <li>• Repeating words or phrases</li> <li>• Hand rubbing, clapping</li> <li>• Re-reading the same book over and over again</li> <li>• Hoarding</li> <li>• Walking to the same place at the same time every day</li> </ul>	

Contact the AFTD HelpLine at  
866.507.7222 or [info@theaftd.org](mailto:info@theaftd.org)

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# Support



2278

HelpLine cases  
in 2017

80

AFTD-affiliated  
support group  
leaders in 31 states

8

AFTD-affiliated  
phone/internet  
groups

180

Comstock grants  
awarded (136  
respite, 44 travel)

**New!**  
**Quality of  
Life Grant  
for persons  
affected**

# Partners in FTD Care

In-depth education on care challenges  
Case-stories, concise strategies & tips

- Challenges in Diagnosis
- ALS / FTD
- Family Participation in FTD Research
- Managing Apathy
- Comfort Care and Hospice



# Research Landscape

FTD is a spectrum of diseases

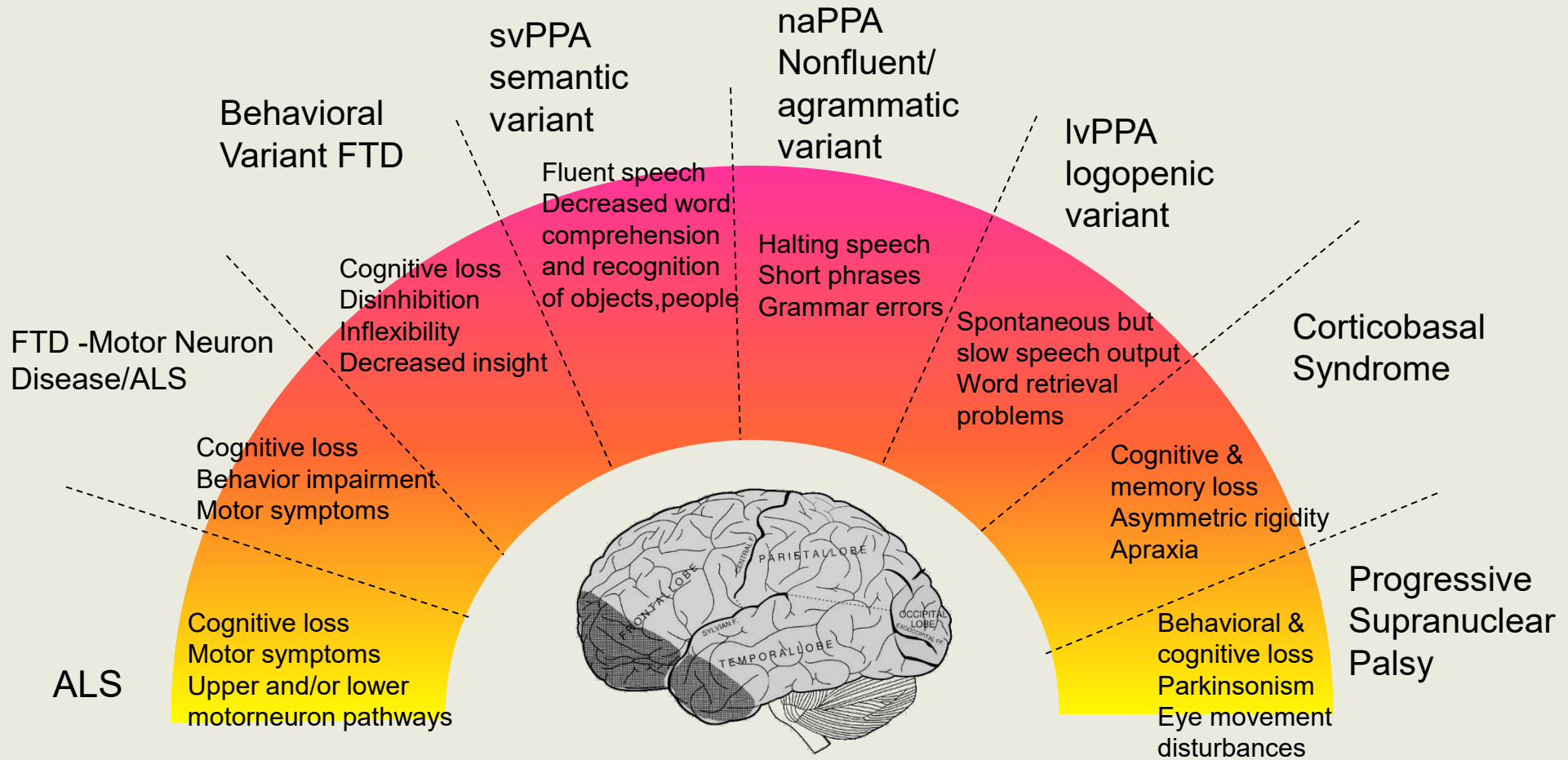
- Diagnosis by clinical syndrome: bvFTD, PPA, CBS, PSP
- Underlying pathology: TAU, TDP-43, FUS
- Approximately 10-20% familial: *MAPT*, *TAU*, *C9ORF72*

FTD can inform other neurodegenerative diseases

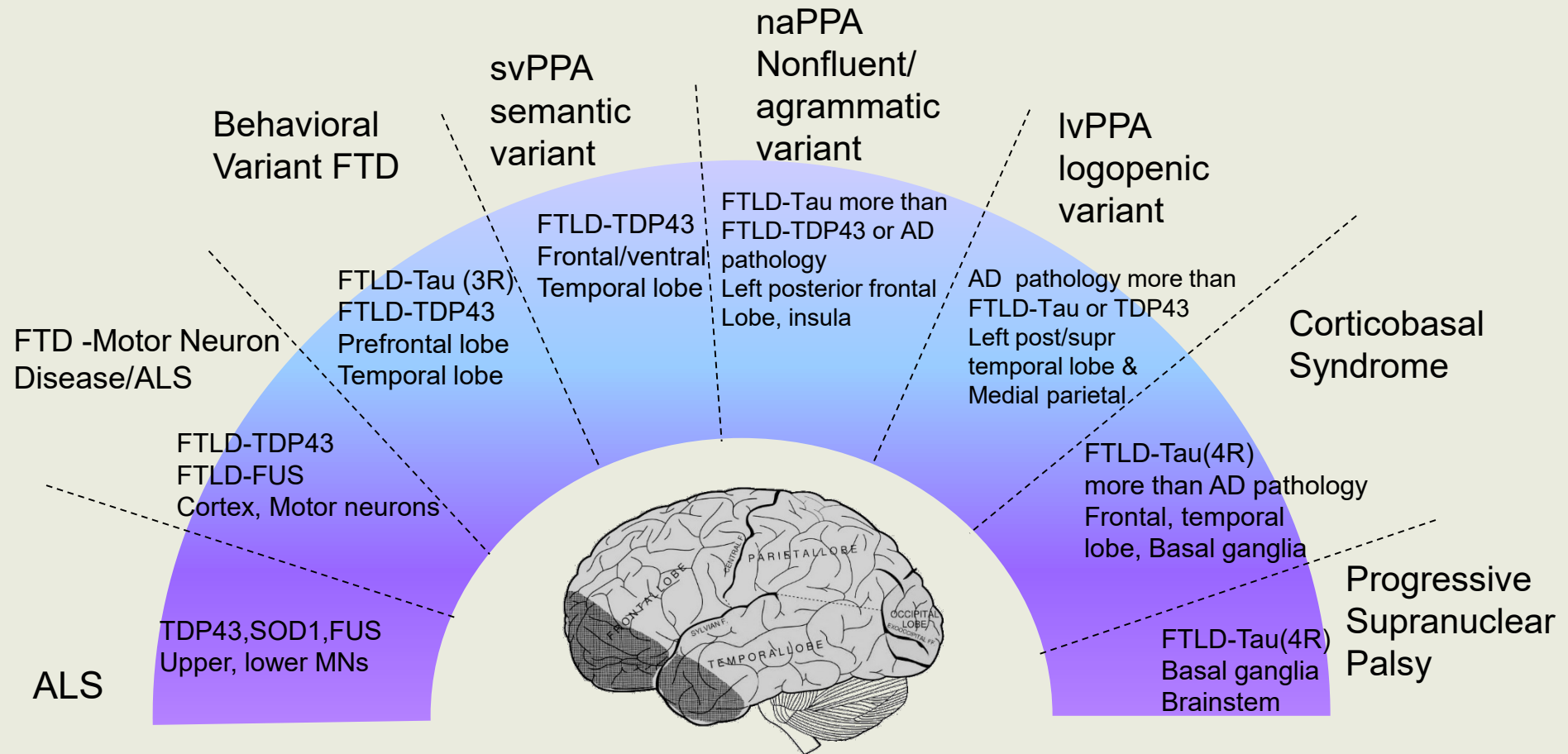
- Tauopathies: PSP, CBD, bvFTD
- C9 in ALS/FTD

ARTFL/LEFFTDS - Rare disease clinical research network

# FTD is a spectrum of diseases



# The FTD spectrum shares proteinopathies and anatomic loci

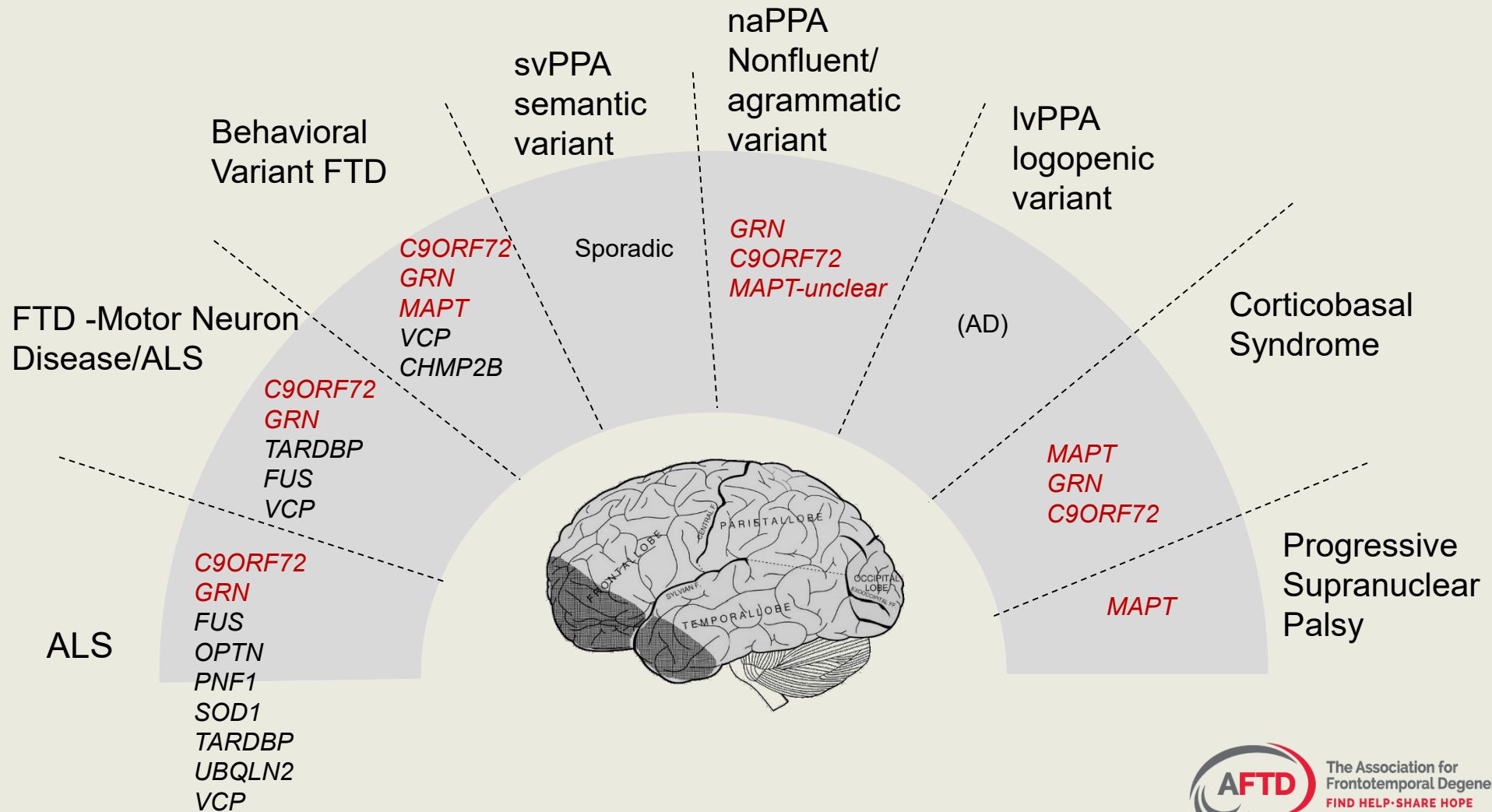




## And A Spectrum of Genetic Causes\*

\*approximately half of all FTD cases have a hereditary component

*C9ORF72, GRN, MAPT* are the most common gene mutations



# Engaging the FTD Community

AFTD's role in research outreach & recruitment

- Co-founded FTD Disorders Registry  
[www.FTDRegistry.org](http://www.FTDRegistry.org); >1950 joined to date
- Strong, unique relationship with those affected
- Flexibility to support recruiting efforts



# FTD Disorders Registry Update

17% of enrolled FTD diagnosed persons report having genetic testing for genes associated with FTD.



20% of FTD diagnosed persons in the Registry are enrolled in other FTD research studies.



6 of every 10 caregivers for an FTD diagnosed person is a spouse.

We asked registrants if they are interested in participating in future research:



**92%** said  
**YES!**

Greater than half of all the FTD diagnosed registrants, *enrolled in the Registry independently.*

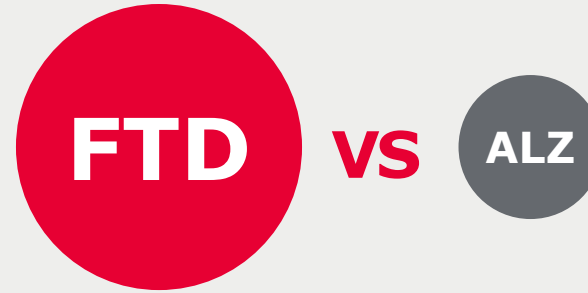


Not enrolled? Join today! [www.ftdregistry.org](http://www.ftdregistry.org)

# Economic Burden Study\*

**\$99k**  
↓  
**\$50k**

Twelve months before an FTD diagnosis, most families reported a household income in the \$75,000–\$99,000 range. Twelve months after diagnosis, income fell as much as 50 percent.



Overall, families dealing with FTD face an economic burden of around  
**\$120,000**  
each year — roughly twice the economic burden of Alzheimer's.

**37%**

of FTD caregivers said they stopped working post-diagnosis.

**58%**

of respondents said that FTD caused their loved ones to make poor financial decisions.

\*Published in the scientific journal *Neurology*, 11/14/17

# Engaging Persons with FTD

Education Conference

Advisory Think Tank

Quality of Life Grants

Medical and Scientific Collaboration

- Educating pharma lived experience
- Inform study design



# Advocacy



National  
Alzheimer's  
Plan





# Research Grant Programs

Portfolio of Active Grants: > \$3 million

- **Postdoctoral Fellowships**
- **Pilot Grants**
- **Biomarkers**
- **AFTD-ADDF Drug Discovery**
- **TreatFTD**



**Haakon Nygaard,  
MD, PhD**  
University of British Columbia



**Kathryn Bowles,  
PhD**  
Icahn School of Medicine  
at Mt. Sinai



**Steven Finkbeiner,  
MD, PhD**  
J. David Gladstone Institutes

**New in 2018! Non-Pharmacological Pilot Grant**

Focus is on innovations in disease management

# New Opportunities

- Listed with Department of Defense on CDMRP 2018 & 2019 grants for FTD disorders
- Membership in FNIH Biomarkers Consortium
- FTD Education Days with industry
- Patient Focused Drug Development meeting with FDA (externally led), submit LOI 2018

# A Community Committed to Change



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