

C Partners in FTD Care

A quarterly newsletter for
healthcare professionals

Spring 2024

CONNECT, LEARN, ENGAGE: AFTD'S 2024 EDUCATION CONFERENCE

AFTD's 2024 Education Conference gives you the chance to gain a better understanding of FTD, learn how to improve care, and hear about all that is happening in research. The conference is taking place in Houston this year, but you can join us virtually as well. Texas is a big state, and we've planned a wide array of sessions focusing on topics of interest to both healthcare professionals and families.

There are more than 20 sessions, including two targeted specifically for healthcare providers. In this issue of *Partners in FTD Care*, we will preview some of this year's conference sessions, using articles from past issues. To learn more about the 2024 AFTD Education Conference, and to register, visit theaftd.org/education-conference-2024. Please join us! ■

KEYNOTE SPEAKER: NEW YORK STATE SENATOR MICHELLE HINCHEY

Michelle Hinchey, a New York state senator representing much of the state's Hudson Valley region, will deliver the Keynote Address at the 2024 AFTD Education Conference.

Sen. Hinchey knows the FTD journey intimately. In 2017, the Hinchey family announced that former U.S. Representative Maurice Hinchey, Michelle's father, was living with a diagnosis of primary progressive aphasia; he died in November 2017 at age 79. Michelle's political career began shortly thereafter – she won her seat in the New York State Senate in 2020 and today represents New York's 41st Senate District.

Sen. Hinchey has been active in pushing for FTD awareness and education throughout New York State. Thanks to a resolution she sponsored shortly after taking office, New York became the first state to officially recognize Frontotemporal Degeneration Awareness Week. Earlier this year, Sen. Hinchey introduced a bill calling for a statewide FTD registry to track new diagnoses in the Empire State. If passed, the registry bill would be a “huge step forward in determining the impact of this disease on communities across the state – and would provide a template for similar legislation in other states,” AFTD Director of Advocacy and Volunteer Engagement Meghan Buzby said.

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KEYNOTE SPEAKER (*continued*)

For years, AFTD has worked with Sen. Hinchey directly to advocate for families facing FTD and educate the public about this too little-known disease. The senator joined AFTD Senior Director of Programs Sharon Denny for an in-studio interview on the NY1 network in 2017. Later, she helped AFTD mark World FTD Awareness Week 2021 by hosting an hour-long Facebook Live event featuring AFTD Advocacy Manager Matt Sharp. And in 2023, AFTD staff, Board members, and volunteers joined Sen. Hinchey to help spread FTD education and awareness among her fellow state lawmakers.

All FTD journeys are different, but they tend to share certain heartbreaking similarities. Misdiagnoses are frustratingly common, and can delay access to crucial care services. But even with a correct diagnosis in hand, simply finding supports that are effective, affordable, and appropriate to FTD care can pose a significant challenge. In her Keynote Address, Sen. Hinchey will talk about her father's FTD journey, from getting a correct diagnosis to securing FTD-specific care. Despite her father's prominence as a member of Congress, Sen. Hinchey and her family still struggled to get him the support he needed.

Many people who have FTD in their lives have found meaning by advocating on behalf of others affected. Sen.

Hinchey has used her platform to educate the public about the disease and to push for legislation benefiting people living with FTD and other dementias. In her Keynote Address, she will talk about the work she has done to help change the FTD narrative through her advocacy – and how others can become empowered to do the same.

Healthcare professionals interested in learning how families facing FTD can convert the raw and painful FTD journey into positive change are encouraged to attend the AFTD Education Conference and hear Sen. Hinchey's powerful story.

Recently, AFTD has expanded our own advocacy program to empower more members of our community to make their voices heard. We encourage you to point families to the [AFTD Advocacy Action Center](#), which allows them to directly tell lawmakers why they should advocate for vital changes that would benefit our community, such as improved access to FTD-specific care and increased funding for research into potential treatments.

In addition to Sen. Hinchey's Keynote Address, other sessions of the AFTD Education Conference will address the importance of advocacy. Whether you plan to come to Houston to attend in person, or prefer to register for the free livestream, we hope you take advantage of the opportunity to learn more about advocating for a future free of FTD. ■

KEYNOTE ADDRESS

**N.Y. State Senator
Michelle Hinchey**

10:00 – 10:30 a.m. CT
In-person and virtual

PAVING THE PATH FORWARD: THE FTD DISORDERS REGISTRY AND AFTD'S ADVOCACY TEAM

**Meghan Buzby, MBA; Susan L-J Dickinson,
MSGC; Carrie Milliard, MS, CGC, CCRC**

11:30 a.m. – 12:00 p.m. CT
In-person and virtual

TAKE ACTION! How to Become an FTD Advocate

**Meghan Buzby, MBA;
Matt Sharp, MSS**

2:00 – 2:45 p.m. CT
In-person

DEVELOPING A PERSON-CENTERED FTD CARE TEAM AND PLAN OF CARE

FTD symptoms can pose unique challenges for professional care providers. Several of this year's AFTD Education Conference sessions focus on better understanding specific FTD disorders and improving care. The following article, on developing a person-centered FTD care team and care plan, is from Partners in FTD Care, issue 34 (Summer 2022).

Successful care for persons living with frontotemporal degeneration (FTD) in a facility setting begins with staff education. This includes training on a broad range of FTD topics, starting from “what is it?” and then covering FTD subtypes, causes, and symptoms; the needs of persons diagnosed; approaches to care; and successful interventions.

Ongoing staff and family participation in the individual's plan of care is crucial. After the initial phase of transition

into the community, staff should continue to rely on the individual's history (including, but not limited to, their medical, social, and psychological background, their primary symptoms, and which care approaches have worked in the past), as well as their current status and needs. This will best position the team to develop and then implement positive care approaches that are individualized, creative, and adaptable as the needs of the person with FTD change.

Creating and updating plans of care that address the individual's changing needs can be challenging. Being open to investigating, testing, and evaluating different approaches, and then clearly communicating the plan with everyone, is critical to success. The following are some recommended approaches to guide person-centered FTD care:

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CONNECT • LEARN • ENGAGE

AFTD 2024 EDUCATION CONFERENCE

**MAY 3, 2024
HOUSTON, TX**

Join the AFTD Education Conference either in Houston or online. No matter how you choose to attend, registration is free.

Visit AFTD's website for a full agenda, a list of speakers, and information on special in-person events happening in Houston.

theaftd.org/education-conference-2024

A Tribute to Jill Shapira, PhD, RN, Partners in FTD Care Advisor

Dr. Jill Shapira, a founding member of AFTD's Partners in FTD Care Advisory Committee, is stepping down from her role. Dr. Shapira has generously shared her expertise and knowledge with AFTD's staff and community since 2011, informing nearly 40 issues of *Partners in FTD Care*. Her contributions will be greatly missed.

At the University of California, Los Angeles, Dr. Shapira worked alongside Dr. Mario Mendez, one of the country's leading FTD experts and an emeritus member of AFTD's Medical Advisory Council. Together, they developed UCLA's neurobehavioral unit, where they specialized in caring for people with FTD and young-onset Alzheimer's disease. During her career, Dr. Shapira designed innovative behavioral management strategies for FTD and coordinated numerous clinical research projects.

Dr. Shapira also presented at multiple AFTD Education Conferences. At the 2013 Education Conference in Salt Lake City she spoke about FTD drug trials, and at the 2019



Education Conference in Los Angeles she facilitated a panel discussion on managing behavioral variant FTD.

All throughout her tenure helping develop Partners, AFTD's community of persons diagnosed, care partners, and healthcare professionals benefited immensely from Dr. Shapira's intelligence and passion for improving the quality of life for all those affected by FTD. Thank you, Jill!

PERSON-CENTERED FTD CARE (*continued*)

COMMUNICATION APPROACHES

- Use basic communication techniques including: speaking slowly and clearly; using simple, shorter sentences rather than open-ended questions; waiting for responses.
- Do not argue with the resident or try to get them to think "logically."
- Smile! Persons with FTD often continue to understand facial expressions. Although the resident may present with no affect, that does not mean they will not respond positively to yours.
- Residents with FTD may connect more with staff (based on age, interests, music) than other residents, who will likely be older.
- For those with communication challenges, create a communication notebook (an album of photos with names of people and objects).
- Use nonverbal communication, including gestures or drawings.

- Use lists of words or phrases that are generally understood and/or often used by them.
- Work with the family or doctor to obtain speech and occupational therapies for assessment and interventions as needed.

BEHAVIORAL APPROACHES

- Do your best to create a low-stimulus environment.
- Avoid overstimulation: limit noise, bright light, number of people, distractions.
- The resident may not think they have FTD. Teach staff that this lack of awareness – known as "anosognosia" – is a hallmark FTD symptom.
- The resident's facial expressions may be blank or appear threatening – do not take this personally.
- Pay attention to nonverbal cues that the person diagnosed is anxious and/or agitated. People with FTD may not show frustration via facial expressions.

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PERSON-CENTERED FTD CARE *(continued)*

PROGRAMMING APPROACHES

- Create and maintain the resident's daily routine; post their schedule for accountability with staff. This may support the resident to engage with activities.
- Individual programs may be more effective than group programs – post their daily schedule in their room.
- If the resident attends group programs, let them sit near the exit so they can easily leave if they become overwhelmed.
- Since persons with FTD may not self-initiate program activity, help them to initiate active involvement when possible.
- Provide a safe outdoor space for the individual to walk or sit.
- Encourage or help to create a personal music playlist for individual activity.
- Note that reminiscence therapy may not be effective, even though memory is typically less impaired in FTD than in other types of dementia.
- Repetitive activities may be effective. Examples include sorting objects (papers, coins, cards, pegs), folding, doing puzzles.
- Invite and include the resident's family in programming as much as possible.

CAREGIVING APPROACHES

- Follow the individual's usual routine. For example, if they bathe or shower first thing in the morning, try not to deviate from that.
- Be aware of the resident's abilities, and encourage independence when possible.
- Provide verbal, visual, and physical cues to encourage initiation of a care activity or task.
- Tell the individual what you are going to do before proceeding. Then go slowly and explain each step.
- Be aware of their personal space. Allow at least an arm's length to provide care from a safe distance.
- Give the resident something to hold while providing care.
- Know that bowel incontinence may occur in early stages of FTD, even before bladder incontinence.
- Adjust your approach to care as the disease progresses. The person diagnosed may not realize they can no longer complete tasks like they used to – you may need to provide encouragement, persuasion, or distraction.
- Consider providing praise or rewards for completed care tasks, whether a favorite activity, food, or beverage, or simply words of encouragement. ■

PRIMARY PROGRESSIVE APHASIA: APPROACHES TO TREATMENT

Maya Henry, PhD

1:00 – 1:45 p.m. CT
In-person and virtual

COGNITIVE CHANGES IN MOVEMENT DISORDERS: CBS AND PSP

Chi-Ying (Roy) Lin, MD, MPH, FAAN

2:00 – 2:45 p.m. CT
In-person and virtual

MANAGING A DUAL DIAGNOSIS OF FTD AND ALS

**Julia Castro, CGC, and
A. Campbell Sullivan, PsyD, ABPP-CN**

2:00 – 2:45 p.m. CT
Virtual only

PROVIDING PROFESSIONAL FTD CARE IN COMMUNITY SETTINGS

*Content targeted to healthcare professionals.
Families welcome.*

Susan Hirsch, MA, Tim Lindsey, and Lindsey Vajpeyi

2:00 – 2:45 p.m. CT
Virtual only

EMERGING TOPICS ON FTD

Our AFTD Education Conference aims to shed light on aspects of FTD diagnosis, treatment, and care that need further analysis and discussion in the research and clinical fields. This year, in-person attendees can view six scientific posters that AFTD and the FTD Disorders Registry have presented at research conferences. These posters are one way AFTD brings the lived experience of FTD to research stakeholders. One of these posters, *Perceptions of Frontotemporal Degeneration (FTD) Experiences among Latino Americans: A Sub-Cohort Assessment of the FTD Insights Survey*, looks at the experiences of a small cohort of Latinx participants who completed our wide-ranging FTD Insights Survey in 2020 and 2021. Additionally, one of our virtual breakout sessions is targeted to healthcare

professionals and will discuss the challenges and successes of clinicians working to improve FTD diagnosis in the Hispanic/Latino community. ■

FTD DIAGNOSIS AND THE HISPANIC/LATINO COMMUNITY

Content targeted to healthcare professionals. Families welcome.

Patricia Garcia, PsyD, MS, Alicia S. Parker, MD, and A. Campbell Sullivan, PsyD, ABPP-CN

1:00 – 1:45 p.m. CT
Virtual only

WHAT TO KNOW BEFORE ORDERING GENETIC TESTING

In approximately 60% of people diagnosed with FTD, no one else in the family has FTD or a related neurological condition. We refer to such cases as “apparently sporadic FTD.” In these individuals, the cause of their FTD is not yet understood. In the other 40% of those diagnosed, more than one person is diagnosed with FTD or a related condition within the same family, a phenomenon known as “familial FTD.” A variety of factors can contribute to one’s likelihood for developing familial FTD, but the most direct cause is an inherited genetic variant passed down from a parent to the child. The following article is adapted from Partners in FTD Care, issue 33 (Winter 2022) and provides thoughtful guidance for healthcare professionals on the importance of genetic counseling for families when considering genetic testing.

Frontotemporal degeneration is a progressive, neurological disorder with no FDA-approved treatments. Because of the seriousness of the condition and the potential implications for extended family members, particular care and consideration need to be given to the emotional, privacy,

and legal/financial needs of the person receiving genetic testing.

Asymptomatic family members of persons diagnosed with FTD often feel distressed when discussing both their risk of developing FTD and the idea of undergoing predictive genetic testing (Wong et al., 2021). Genetic counselors can help people to better understand the goals of genetic testing, review their family history, and provide a risk assessment. AFTD recommends those considering genetic testing first be referred to a genetic counselor.

Our understanding of FTD’s causes has grown greatly over the last 20 years. Thirty to fifty percent of people diagnosed have a family history of dementia, a major psychiatric condition, or progressive challenges in movement. A subset of these familial cases is genetic, or hereditary, in nature (Goldman & van Deerlin, 2018). FTD is genetically heterogeneous, with at least 13 genes associated with autosomal dominant inheritance. Three genes account for

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BEFORE ORDERING GENETIC TESTING (*continued*)

the majority of genetic FTD: *MAPT*, *GRN*, and *C9orf72*. Because FTD can be inherited, many people who have a family member diagnosed with FTD want to learn more about the genetic risk of getting FTD themselves.

Clinicians may recommend genetic testing in the presence of a strong family history or certain clinical presentations, as in the case of FTD-ALS. Because family history may not be complete or conclusive, all persons diagnosed with FTD should be offered genetic counseling to help get answers and assuage any concerns they or their family might have (Goldman & van Deerlin, 2018). For many people, learning their genetic status can relieve anxiety resulting from uncertainty.

The lack of disease-modifying treatments in FTD can lead to increased stress around testing (Roggenbuck, Quick & Kolb, 2017). However, as potentially disease-modifying treatments in FTD enter clinical trials, people with known genetic variants can participate and advance the science of FTD.

Those considering genetic testing face many complex considerations; their empowerment and emotional well-

being are of the utmost priority. Individuals decide to undergo genetic testing for different reasons; a person's genetic status can inform their financial future, the decision to raise a family, and other important life decisions. Regardless, the decision to undergo genetic testing is highly personal, and necessary support should be offered. ■

SOURCES

Goldman, JS, & Van Deerlin, VM (2018). Alzheimer's Disease and Frontotemporal Dementia: The Current State of Genetics and Genetic Testing Since the Advent of Next-Generation Sequencing. *Molecular Diagnosis & Therapy*, 2018; 22(5), 505–513. <https://doi.org/10.1007/s40291-018-0347-7>.

Roggenbuck, J, Quick, A, & Kolb, SJ. Genetic Testing and Genetic Counseling for Amyotrophic Lateral Sclerosis: An Update for Clinicians. *Genetics in Medicine*, 2017; 19(3), 267-274.

Wong, B, et al. Knowledge Assessment and Psychological Impact of Genetic Counseling in People at Risk for Familial FTD. *Alzheimer's & Dementia*, 2021; 13(1): e12225.

GENETIC FTD RESEARCH: A TOWN HALL

Penny Dacks, PhD

1:00 – 1:45 p.m. CT
In-person only

TALKING TO YOUR FAMILY ABOUT GENETIC FTD

Julia Castro, CGC and
Jamie Fong, MS, CGC

3:00 – 3:45 p.m. CT
In-person and virtual

FTD RESEARCH: FROM FUNDING TO FRUITION

Alinka Fisher, PhD, Laura Mitic, PhD,
and Regina Shin, PhD

4:45 – 5:15 p.m. CT
In-person and virtual



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