

C Partners in FTD Care

A quarterly newsletter for
healthcare professionals
Spring 2023

CONNECT, LEARN, ENGAGE: AFTD'S 2023 EDUCATION CONFERENCE

A FTD's annual Education Conference is a unique opportunity for healthcare providers to hear the insights, perspectives, and stories of people living with FTD and their care partners. Whether you attend in person or virtually, you will gain a better understanding of what it means to live with FTD. The conference also gives you the opportunity to hear from national experts on emerging issues in FTD diagnosis, treatment, and care. This is especially important as healthcare settings continue to strive to achieve person-centered care that starts with the goals of the individual diagnosed, instead of prescribing a cookie-cutter approach to treatment based on their diagnosis.

Past attendees often say that the most impactful element of the conference is meeting and talking to others on the FTD journey. AFTD has historically worked with families, healthcare professionals, researchers and others across the country to create a community of care and support. We invite you to join AFTD and this caring community at our **May 5th** conference. Insights from the conference often travel back with professional attendees, bringing new understanding and meaning to their work.

In this issue of *Partners in FTD Care*, we will preview some of the conference topics and introduce speakers using updated articles from past issues. To learn more about the 2023 AFTD Education Conference, visit theaftd.org/education-conference-2023.

KEYNOTE SPEAKER: BRUCE MILLER, MD

Internationally recognized FTD expert Dr. Bruce Miller will deliver the Keynote Address at the 2023 AFTD Education Conference. An emeritus member of AFTD's Medical Advisory Council, Dr. Miller's impassioned search to unravel the complexities of FTD and understand the unique challenges and abilities of those with a diagnosis has advanced research, treatment, and care.

The UCSF Memory and Aging Center, which he directs, is a nationally respected FTD research and clinical care site. The center supports those with FTD and their care partners to engage in research, obtain a comprehensive diagnosis, and create an individualized treatment and care plan. Dr. Miller is also the founding director of the Global Brain Health Institute, which supports value-based leadership in science, art, and policy to improve dementia care and advance brain health around the world.

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KEYNOTE SPEAKER (*continued*)

In his Keynote Address, “Recent Advancements and the Hope Ahead,” Dr. Miller will speak about developments he has seen in the fields of FTD care and research throughout his career. He will highlight the most challenging issues we face now and share his reasons for hope.

In his profile on the Global Brain Health Institute website, Dr. Miller shares that one of his heroes is Bob Dylan. To paraphrase one of Dylan’s songs, we might say that “the times they are a-changin’” in the world of FTD research. For most of us, that change cannot come fast enough. Still, there is an increasingly global family and research community focused on finding answers. Members of that global community are likely to be in attendance at AFTD’s 2023 Education Conference -- our 2022 conference had the most international attendees in the event’s history, reaching audiences in 28 countries. We are looking forward to Dr. Miller sharing his insights with our local, national, and global community.

Dr. Miller frequently shares his extensive FTD experience as a popular teacher and mentor to clinicians studying diagnosis and disease progression, and with the general public. He founded the Behavioral Neurology Fellowship at UCSF, which coordinates visits of more than 50 foreign scholars each year. He has also been featured in the *New York Times*, *Fortune*, and *PBS NewsHour*, as well as a 2019 *60 Minutes* story on FTD.

Do not miss the opportunity to hear from a global leader in FTD research, treatment, and care.

KEYNOTE ADDRESS: RECENT
ADVANCEMENTS AND THE HOPE AHEAD

Bruce Miller, MD

University of California, San Francisco

A.W. and Mary Margaret Clausen Distinguished
Professor of Neurology

Director, Memory and Aging Center, UCSF

Founding Director, Global Brain Health Institute

10:15 – 10:45 a.m. CT

INSIGHTS FROM AFTD'S PERSONS
WITH FTD ADVISORY COUNCIL...

The one thing I think we all have in common after we hear the words “I think you have FTD” is a decline of inclusion in society. People stop listening to us or asking for our opinions, and we feel shunted to the outer edges of social activities.

– Bob, AFTD’s Persons with
FTD Advisory Council

A PERSONAL INVITATION TO HEALTHCARE PROFESSIONALS TO ATTEND THE AFTD EDUCATION CONFERENCE



**By Anne Fergusson, RN,
co-chair, AFTD
Persons with FTD
Advisory Council**

To any doctors, nurses, specialists, or other healthcare professionals reading this: I would like to personally invite you to join us at the 2023 AFTD Education Conference on May 5th, either in person in St. Louis, Missouri,

or online via livestream. As someone living with an FTD diagnosis and a former nurse, I know how important it is when healthcare professionals take the time to understand the journey from the lived experience of people like me.

Because FTD is often a young-onset dementia, its impact on the person diagnosed and their family can be overwhelming.

At the Education Conference, persons with the disease will talk about that impact, which can include the loss of a job, income, friends, and family members, as well as other daily struggles. Sometimes the grief and guilt take their toll on everyone involved. And then there is the shaming from others, including sometimes those assisting in our care. Most who have FTD experience extreme isolation and depression along with the stigma that comes with this diagnosis.

The AFTD Education Conference is an opportunity to better help those living with FTD. At the conference, you will learn about the different forms of FTD and how to identify someone with this disease. Informational resources about caring for persons with FTD will be available. You will also learn more about the FTD Disorders Registry, and other opportunities for research. In-person attendees will have the ability to network with other professionals.

On behalf of the entire AFTD Persons with FTD Advisory Council, I invite you to join us at the Education Conference so you can learn, connect, and engage with people impacted by this disease.

CONNECT • LEARN • ENGAGE

AFTD 2023 EDUCATION CONFERENCE

**MAY 5TH, 2023
ST. LOUIS, MO**

If you are unable to make it to St. Louis, you can livestream the conference online. The AFTD Education Conference is free of charge, whether you attend virtually or in person.

Visit AFTD's website to learn more about special pre-conference sessions and networking opportunities available for in-person attendees, including a session on familial FTD.

theaftd.org/education-conference-2023

DESIGNING INTERVENTIONS FOR APATHY

The symptoms and behaviors associated with FTD can pose challenges for families and healthcare professionals. Some sessions at the 2023 AFTD Education Conference will present ways to better prepare for and respond to these behaviors. The article below on addressing apathy, a common and potentially challenging symptom, is excerpted from issue 23 of Partners in FTD Care (Winter 2018).

Designing approaches based on the specific nature of a person's apathy can increase goal-directed activity. The closer the fit between the reason for inactivity and the intervention, the greater the effectiveness of the intervention.

Individuals with initiation difficulty may benefit from Multi-Sensory Stimulation (MSS), a therapeutic approach that provides visual, auditory, tactile, and olfactory stimulation, and external sensory cueing. For example, to use MMS to encourage someone to shower, use a verbal cue (e.g. "It's time for your shower"), show the individual a checklist or schedule and/or the bathing area, provide lavender aromatherapy soap, and help them to feel the water before showering. Introduce these one at a time. Playing warm, soft music while minimizing distractions in the bathing environment can also increase initiation.

When the person diagnosed has difficulties with planning, try simplifying their activities. Consider providing just one or two choices to limit overwhelming decision-making. Develop and post a daily schedule of preferred activities. Include quiet time or rest. If the person diagnosed can use a smartphone, it may help to schedule reminders to perform certain activities. Tailor a person's past interests to their current level of ability; for example, if they enjoyed playing full-court basketball, get them a small hoop. Remember that confusion and frustration contribute to inactivity.

Individualized planning is central to interventions when motivation difficulties are present. For patients with impaired goal selection, modifications such as enhancing rewards may be useful. For example, individuals with behavioral variant FTD (bvFTD) often find food rewarding. Therefore, offering a favorite sweet or chewing gum may be a good motivator.

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I want to be able to contribute to meaningful conversations, but there are times when I get lost in the conversation and am unable to understand what is being said. Once I begin to disconnect, I ask the person speaking to slow their speech down so that I can better follow what is being said.

– Teresa, co-chair, AFTD's Persons with FTD Advisory Council



INTERVENTIONS FOR APATHY (*continued*)

Two interventions—music therapy and physical activity—can be effective strategies for general apathy. Create a personalized music playlist. Adapt interests in fitness or sports to help the person remain as active as possible.

In addition to understanding the components of apathy, knowing specific strengths and challenges of the various subtypes of FTD disorders will influence how you communicate and engage with the person diagnosed. Providing structured steps for activities may be important

for an individual with primary progressive aphasia; due to their difficulty understanding everyday speech, they can become easily overwhelmed. Simplifying your communication—speaking at a slowed rate, using shorter sentences, omitting unnecessary words—can also enhance comprehension. People with bvFTD often respond well to following an established routine of structured, repetitive activities—sorting papers, coins or cards; folding laundry; doing puzzles.

UNDERSTANDING AND APPROACHING bvFTD SYMPTOMS

Stacey Barton, MSW, LCSW

11:45 a.m. – 12:30 p.m. CT
In-person breakout session

RESPONDING TO HIGH-RISK BEHAVIOR IN FTD

Jennifer Pilcher, PhD

3:15 – 4:00 p.m. CT
Virtual breakout session

TROUBLES & TIPS: CREATING A VILLAGE OF SUPPORT

Below is an edited excerpt from Partners in FTD Care, Issue 18 (Spring 2016), which provides guidance for supporting families and children facing FTD together.

What can healthcare professionals do when working with families that have young children and teens? People facing FTD have a heavier burden of care than in other dementias, due to the younger age of onset, the presence of behavioral symptoms, and a general lack of awareness and understanding of the disease. When there are young children or teens in the home, the level of support needed is particularly high. “It takes a village,” as they say. Healthcare professionals can play an important role with families that include a parent diagnosed with FTD.

In 2011, a special AFTD Task Force on Families conducted a survey of young adults who, as children or teens, lived with a diagnosed parent. Respondents described the most difficult-to-manage aspects of their family’s FTD journey:

- 1) Behavioral symptoms
- 2) Loss of an established relationship
- 3) Thinking and communication symptoms
- 4) Caregiving responsibilities

Special care is needed for children to succeed in school and navigate social adjustment with their peers, all while trying to understand what FTD is and cope with a radically altered home life. Depending on the age and development level of the children, isolation can be a big factor. Engaging with peers who face similar circumstances can ensure they feel connected to others and reduce this isolation.

Healthcare professionals can facilitate a more positive experience by working to understand the symptoms and impact of FTD as well as how the specific family they are treating is coping. Healthcare professionals should know about additional counseling options, social services available through schools, and other resources, so that they can recommend such services as appropriate for younger families.

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PARTNERS IN FTD CARE ADVISORS

The Partners in FTD Care initiative is the result of collaboration among AFTD, content experts, and family caregivers. Advisors include:

- **Sandi Grow, RN**, former FTD caregiver, AFTD Board member
- **Lisa Gwyther, LCSW**, Duke Family Support Program (retired)
- **Susan Hirsch, MA**, ProMedica Senior Care

- **Mary O'Hara, LCSW**, University of Colorado Medicine
- **Jill Shapira, PhD, RN**, UCLA FTD and Neurobehavior Clinic (retired)

For permission to reprint this material in whole or in part, contact Esther Kane, AFTD Director of Support & Education, at ekane@theaftd.org. To join the Partners in FTD Care mailing list, or to view the full archive of back issues, visit www.theaftd.org/for-health-professionals/partners-in-ftd-care

TROUBLES & TIPS (*continued*)

Encourage parents to empower children to make their own decisions. For example, if there are multiple household tasks that need to be completed – some dealing with the caregiving role, some more chore-related – allowing the children to choose which tasks they feel most comfortable doing will help them feel less overwhelmed or burnt out.

Additionally, children should be permitted to make their own decisions about visiting a parent who is in a facility, including when they visit and for how long.

Communication is also important. Encourage parents to engage in open, honest, age-appropriate dialogue with their children. Healthcare professionals should coordinate with the adults in the family to ensure that the information they choose to share with the children is consistent. Children need to know it is safe to ask questions and voice their feelings, concerns, and needs. Children should also be able to decide whether and how to talk to friends about their parent's diagnosis.

Between working, providing care for their spouse or partner, and managing the household, non-diagnosed parents may display limited emotional availability. Healthcare professionals may want to encourage the non-diagnosed parent to choose another trusted adult that their children can consider a surrogate parent, to give the children more individualized time and attention.

Children may naturally ask whether FTD runs in their family, but parents may not feel equipped to answer.

Professionals on the care team of the person diagnosed should point them to AFTD's website and/or HelpLine for guidance on how to respond in an accurate and age-appropriate way.

Healthcare professionals working with persons with FTD in residential care settings should creatively brainstorm with the non-diagnosed parent ways to support their children. Visualize the experience through the eyes of a teen or younger child; the perspective will vary depending on the child's age. Arrange a private space for children to visit with their parents, and encourage simple, familiar activities whenever possible. The facility's activity director may be able to incorporate groups of children in their activities or performances. The care team may benefit from knowing how often the parent plans to bring the children, making sure that there is a mechanism in place to determine how the visits are going and evaluate the resident's response.

WHAT COMES NEXT: SUPPORTING KIDS AND TEENS AFTER AN FTD DIAGNOSIS

Diana Cose
Tessa Garcia McEwen, AM, LCSW, CDP
Bree Ruge, CDP

11:45 a.m. – 12:30 p.m. CT
In-person and virtual breakout session

FTD RESEARCH: URGENTLY NEEDED, UNIQUELY CHALLENGING

Healthcare professionals play a pivotal role in helping families to learn about and participate in FTD research. Following is an updated version of an article originally published in issue 21 of Partners in FTD Care (Spring 2017) that addresses how healthcare professionals can best support families who want to help advance the science of FTD.

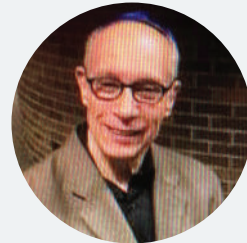
Research into FTD has gained momentum in recent years, with numerous active clinical trials, observational studies, and other notable scientific advancements. Many promising potential therapies to improve symptom management or slow down or stop disease progression are currently being studied, as are urgently needed diagnostic tools and biomarkers. It is important that studies enroll enough participants to allow this research to continue. At this pivotal moment, healthcare providers play a critical role in opening the door to research opportunities for persons diagnosed and their families.

Families who choose to take part in FTD research often hope that the results will help others, even if they themselves don't directly benefit. Participating in research can present certain challenges, however, and you can help families to be prepared. For example, families need to be aware of the demands of participating in FTD research. With preparation, many of the challenges associated with those demands can be reduced.

Because relatively few people have an FTD diagnosis, every person who contributes to FTD research can make a big difference. Potential benefits to participating in research include:

- To learn more about one's condition – for example, by receiving results of certain tests conducted as part of research.
- To help future generations by furthering our understanding of how to diagnose, prevent, treat, or cure FTD.
- To take an active role in one's own healthcare.
- To gain access to interventions, specialists, or assessments that may not otherwise be available.
- To potentially improve one's condition or quality of life.

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Ten years ago I was diagnosed with behavioral variant FTD. I was told by professionals and loved ones that within six months I would no longer recognize close family members and would need to be institutionalized for the rest of my life. Right away I became fearful and anxious about losing my memory and coping skills.

– Steve, AFTD's Persons with FTD Advisory Council

FTD RESEARCH (continued)

CURRENT RESEARCH OPPORTUNITIES

Opportunities to participate in research are available for people diagnosed with any FTD subtype, past and current caregivers, and biological relatives of people with FTD. Research opportunities vary widely in eligibility criteria, duration, types of interventions, and remote participation options. Here are some ways to take part:

FTD Disorders Registry: The Registry (FTDregistry.org) is designed to inform people with FTD, their families, and their caregivers about research opportunities, matching them to studies actively seeking participants. Registry participants retain full control over their identifying information, which is never shared. Healthcare providers can also sign up for the FTD Disorders Registry newsletters, which provide key updates in FTD research.

Natural History Studies: In natural history studies, researchers observe participants over time and document the changes in their health. Funded by the National Institutes of Health, the ALLFTD natural history study consists of 23 sites across the United States and Canada that enroll persons diagnosed with a variety of FTD-related disorders, as well as undiagnosed people with a family history of FTD. Participation typically involves yearly in-person assessments and procedures such as interviews and neuroimaging. ALLFTD participation may include help accessing genetic counseling/testing and brain donation. Visit allftd.org to learn more.

Clinical Trials: This type of clinical research study is used to test a new treatment, diagnostic tool, or prevention strategy. To minimize the possibility that irrelevant factors will confuse the study results, researchers develop strict eligibility guidelines. Not everyone who would like to participate will be able to do so. The most common clinical trials are those that evaluate new medications, also known as drug trials. For more information on clinical trials and other research opportunities, visit www.theaftd.org/research-clinical-trials/featured-studies and www.ftdregistry.org/find-a-study.

Genetic Counseling: Currently, there are a number of clinical trials testing experimental treatments for FTD caused by specific genes. To learn more about FTD genetics, and how genetic counseling can help determine if families are eligible for these clinical trials, visit www.theaftd.org/ftd-genetics/what-causes-ftd and www.ftdregistry.org/genetics-ftd.

Brain Donation: Another way to participate in research is to make a brain donation to an FTD research center or a brain bank, a facility that collects and stores donated brain tissue for future research. Brain donation requires planning. Each center has criteria for enrollment and study protocols. Upon enrollment, families should confirm if they will receive a pathology report. If a person qualifies for the research program, there may be little cost to the family, but the details of what is and is not reimbursed should also be confirmed with the brain bank. For more information, visit www.theaftd.org/research-clinical-trials/ways-to-participate/brain-donation.

PROMISING PATHS TO DISCOVERY

Qinwen Mao, MD, PhD
Matthew Nolan, PhD
Emiliano Santarnecchi, PhD

1:45 – 2:15 p.m. CT
In-person and virtual

SHARING YOUR EXPERIENCES TO ADVANCE FTD SCIENCE

Adrian Eissler
Susan Eissler
Nupur Ghoshal, MD, PhD
Sweatha Reddy
Deb Scharper
Terry Walter

3:15 – 4:00 p.m. CT
In-person and virtual

UNDERSTANDING THE UNIQUE NEEDS OF FTD CARE PARTNERS

Joseph Gaugler, PhD
Allison Lindauer, PhD
Darby Morhardt, PhD

4:30 – 5:00 p.m. CT
In-person and virtual

HOW HEALTHCARE PROFESSIONALS CAN SUPPORT RESEARCH PARTICIPATION

- Let the person diagnosed and family members know there are current research opportunities to better understand FTD, to improve quality of life for people impacted by FTD, and to potentially slow or stop the progression of FTD.
- Inform families about options for genetic counseling to determine if genetic testing may be right for them.
- Encourage families to share their motivation to participate in research with other families, care managers, and facility staff who may not understand why research participation is so important to the family and all those affected.
- Help the caregiver identify what resources are available to support participation, such as financial help, as they may be consumed by caregiving and not able to investigate fully.
- Assist the primary caregiver to gather necessary medical history, clinical evaluations, and test results.
- Provide emotional support to those who wish to participate but are ineligible, or who are distraught when they must discontinue due to disease progression.
- Ensure that family and clinical staff always have access to the steps necessary for brain donation. Donation for research must be done within 24 hours after death.
- Discuss brain donation early with the person diagnosed and their family rather than waiting until end of life.

Scientists are closer than ever to new therapies and diagnostic tools for FTD. We all have a role to play in helping the research succeed.



Unfortunately, the FTD “fatigue factor” is difficult for some caregivers, family members, and friends to comprehend: “You did this last week. Stop being lazy and just do it.” When my brain is exhausted, I am lucky if I can remember how to do only one thing. One does not have to be in advanced stages to be unable to do things. We may just be more tired than usual and need understanding and patience.

– Cindy, AFTD’s Persons with FTD Advisory Council