

AFTD Education Conference & Annual Meeting 2014

Friday, March 14, 2014 10 a.m. - 6 p.m.

Crowne Plaza White Plains 66 Hale Avenue White Plains, NY 10601

Hosted by:



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



<u>Special thanks to our</u> Kids and Teens Website Sponsors:

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Dear Friends,

On behalf of The Association for Frontotemporal Degeneration, I am pleased to welcome you to our 2014 Education Conference and Annual Meeting! I hope that you will find today to be both informative and encouraging. Becoming educated about FTD is one of the most helpful things you can do as either a caregiver or someone who is affected. While it is a difficult disease with many intricacies, having a solid knowledge base about FTD will be beneficial as you speak with doctors

and move forward. It's also important to connect with others who understand your journey. The people you meet during today's sessions and at this evening's reception have all experienced life with FTD from one perspective or another. It is important to come together to draw strength and understanding from one another.

This day would not be possible without generous contributions from our sponsors and caring individuals. I would like to extend special thanks to Dr. Ted Huey and the staff at Columbia University's Taub Institute, whose support of this conference has been invaluable. The Taub staff and additional colleagues have dedicated significant time to developing this program, and they join us today as facilitators and distinguished guests. Additional financial support for the day has come from sponsors who are recognized on the previous page, including our presenting sponsor, TauRx. To all of these generous partners, we give our sincere thanks.



We're thrilled to have former NBC Chief Health and Science Correspondent Robert Bazell as our keynote speaker today. Mr. Bazell's final NBC Nightly News segment in June 2013 aired just before he retired from NBC and featured AFTD Board Member John Whitmarsh and his wife Barbara, who is diagnosed with FTD. Mr. Bazell's speech promises to empower all of us as we strive to "make ourselves heard."

Finally, if your personal circumstances permit, I encourage you to join us in our important work. Every individual that finds a way to contribute time, talent or treasure strengthens our community, and speeds us to realizing our vision of:

A world where FTD is understood, effectively diagnosed, treated, cured and ultimately prevented.

Warm regards,

1 Jarsen

Jary Larsen, Ph.D. AFTD Board Chair



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

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The Day's Program

<u>The Day's Program</u>		Reaching
		New
Registration	9:00	Heights
Welcome Jary Larsen, Ph.D., AFTD Board Chair	10:00	
FTD Overview, Trends and Development Edward Huey, M.D., Columbia University Assistant Professor, Departments of Psychiatry a	10:10-11:00 and Neurology	AFTD Conference 2014
Hot Topics in the Field: The Importance of Jill Goldman, M.S., M.Phil., CGC, Columbia Un Nadine Tatton, Ph.D., AFTD		n 11:00-11:30
Q&A with Morning Speakers Edward Huey, M.D., Columbia University Jill Goldman, CGC, Columbia University Nadine Tatton, Ph.D., AFTD		11:30-12:00
Lunch		12:00-1:00
AFTD Annual Meeting Susan Dickinson, M.S., CGC, AFTD Executive	Director	1:00-1:45
Tour of Website for Children & Teens Catherine Pace-Savitsky and Olivia Goldring		1:45-2:00
Breakout Sessions		2:15-3:45
Break		3:45-4:00
Panel Discussion - Insight to Action Current and former caregivers and a person with FTD Howard Glick, David Murrow and Eleanor Vaug	han	4:00-4:50
Keynote Address: Making Yourselves Heard Robert Bazell, former NBC Chief Science & He		5:00-6:00
Reception Hosted by AFTD Board		6:00-8:00
Stay for food & drink and conversation with today's speakers	;, AFTD Board & staff, a	and most importantly, each other.

Breakout Session Overview

Register for the breakout session that best fits your interest and needs.

Framework for Moving Forward: For people adjusting to a relatively recent diagnosis of FTD. Participants will hear medical, social worker and first-person perspectives about the services and support that can help them move ahead in their new role.

Host: Bonnie Shepherd, AFTD Board Member Led by: James Noble, M.D.; Eleanor Vaughan; Kerri Barthel, M.S.W.

Understanding and Coping with Language Changes: For people concerned about symptoms of primary progressive aphasia in early and moderate disease. Facilitators will address how language assessment and speech-language therapy techniques can maximize communication as the disease progresses. Ron and Sally show how taking on PPA openly has helped them manage changes.

Host: Lisa Radin, AFTD Board Member *Led by:* Melanie Shulman, M.D.; Ellayne Ganzfried, M.S., CCC-SLP; Ron and Sally Kinnamon

Understanding and Coping with Behavior Changes: For people concerned with behavior changes at home, in the community and in residential care. Facilitators will discuss management strategies and community resources, and invite discussion with experienced caregivers on how they cope with changes due to the disease.

Host: Beth Walter, AFTD Board Member Led by: Edward Huey, M.D. and Connie Wasserman, LCSW

Comfort Care and End of Life Considerations: For people caring for a loved one with advanced FTD. Facilitators will address symptom progression in moderate to advanced dementia, practical tips for managing increasing care needs, resources available for support and the importance of addressing end of life decisions.

Host: Debbie Fenoglio, AFTD Board Member Led by: Rebekah Wilson, M.S.W.; Brett A. Steinberg, Ph.D., ABPP; David Murrow

Making a New Life After Being Diagnosed: For people diagnosed with an FTD disorder who are interested and able to participate on their own behalf. Participants will meet others living with FTD to share experiences, coping strategies and support.

Led by: Howard Glick; Stephanie Cosentino, Ph.D.; Sharon Denny, M.A.; Matthew Sharp, M.S.S.

Speaker Bios

Kerri Barthel, M.S.W., joined AFTD as Volunteer Manager in September of 2012. She has over 13 years of experience advocating for and supporting the needs of individuals with life-threatening and debilitating diseases and their families. Her extensive background includes developing and implementing effective programs and a passion for volunteering. Her volunteer work includes spearheading and managing a grassroots advocacy coalition in Pennsylvania for four years and completing two international missions through Doctors Without Borders. Kerri's skills and experiences will be used to strengthen and develop the AFTD volunteer network.

Stephanie Cosentino, Ph.D., is Assistant Professor of Neuropsychology in the Division of Aging and Dementia at Columbia University Medical Center, Department of Neurology. Dr. Cosentino's clinical work focuses on the diagnosis of age-related neurodegenerative diseases. In her research, she examines the cognitive, behavioral and metacognitive profiles of various diseases, particularly Alzheimer's disease and frontotemporal degeneration (FTD) and the specific factors that contribute to heterogeneous clinical profiles within these diseases.

Sharon S. Denny, M.A., is Program Director for AFTD where she leads support and education efforts for people with FTD, their families and professionals. Her priorities include ensuring the responsiveness of the HelpLine and expanding the information and resources AFTD provides. She has introduced initiatives to address the needs of children and teens and support for people with the disease. In 2011, a committee of clinicians and family caregivers created Partners in FTD Care as an on-going effort to educate community healthcare providers and promote best practices in FTD care. Sharon has a Master's in clinical psychology and more than 25 years' experience in program development for disability organizations. She has been with AFTD since 2008.

Susan Dickinson, M.S., CGC, joined AFTD as Executive Director in February 2008. She is a certified genetic counselor who brings more than 20 years' experience facilitating communications among lay, scientific and medical communities. During her tenure at AFTD, the organization has implemented an aggressive strategy for growth, more than tripling its budget and expanding its professional staff from three to nine. Susan holds an M.S. in genetic counseling from Arcadia University and a B.A. in biology and psychology from Swarthmore College.

Ellayne S. Ganzfried, M.S., CCC-SLP, is a speech-language pathologist and the Executive Director of the National Aphasia Association. She is Past President of the NYS Speech Language Hearing Association (NYSSLHA), Long Island Speech Language Hearing Association (LISHA) and the Council of State Association Presidents for Speech Language Pathology and Audiology (CSAP) and remains active in these associations. Ellayne is a Fellow of the American Speech Language Hearing Association (ASHA). She was a site visitor for ASHA's Council on Academic Accreditation (CAA) and a practitioner member of the CAA for four years. She is currently on ASHA's Committee on Honors. Ellayne has created and managed several speech, hearing and rehabilitation programs in New York and Massachusetts. She is an adjunct instructor at Adelphi University-Garden City, NY. Ellayne has written articles and presented regionally and nationally on a variety of topics including aphasia, rehabilitation and leadership skills.

Howard Glick was diagnosed with FTD in 2010 following 6 ¹/₂ years of being diagnosed with and treated for bipolar disorder. After an initial adjustment to his new diagnosis, Howard decided to devote his energy to raising awareness and helping others also diagnosed with FTD. Howard writes a blog about his experiences that has exceeded 121,000 page views and moderates a Facebook group for people with FTD that has 87 members. In 2014, Howard's blog was included as part of an online archive of web content being built by the U.S. National Library of Medicine (NLM) to collect, preserve and make available to the public materials that provide information in medicine and public health. Since September 2011, he has been working with thinkfilm, inc. on "Howard's Brain," a film that will help the public understand FTD from a patient's point of view. Howard, once a successful businessman, is a divorced father of two who lives in Scottsdale, AZ and manages his own care.

Jill Goldman, M.S., M.Phil., CGC, is a genetic counselor at Columbia University Medical Center's Taub Institute for Research on Alzheimer's Disease and the Aging Brain. She counsels and does research on the genetics of neurological conditions. Her particular areas of interest are atypical dementias, especially frontotemporal dementia, and the ethical aspects of genetic testing and genetic research. She leads two support groups in conjunction with the Alzheimer's Association: a group for early-stage dementia patients meeting at the Metropolitan Museum of Art and a group for FTD caregivers. Jill holds a Master's degree in genetic counseling from the University of California, Berkeley and a master of philosophy in biology from Yale University.

Edward (Ted) Huey, M.D., joined the faculty of Columbia University's College of Physicians and Surgeons in 2010 as Assistant Professor of Psychiatry and Neurology. Dr. Huey's research has focused on the genetics of frontotemporal degeneration (FTD) and he is interested in the range of phenotypes associated with mutations that can cause FTD. He also uses imaging in patients with FTD and brain injury to explore the neuroanatomy of complex behavior, neuropsychiatric symptoms and emotion in patients with brain dysfunction. A third interest is in the role of the dopamine system in the pathogenesis and treatment of FTD symptoms. He is the recipient of an NIH/NINDS Pathway to Independence Award to research novel medication treatments and imaging biomarkers for frontotemporal lobar degeneration (FTLD). He sees patients in the Lucy G. Moses Center for Memory and Behavioral Disorders of the Neurological Institute and in the Memory Disorders Center of the New York State Psychiatric Institute.

Ron Kinnamon did his undergraduate studies at Southern Methodist University and went on to get his Master's degree in Group Work Administration at George Williams College. He also did some training with the American Management Association. For a career of 38 years, Ron was a YMCA Executive, retiring as the Assistant National Executive. He was called upon to give many speeches and presentations around the world. He has been very involved at a board of director level with numerous not-for-profit institutions including America's Promise, Points of Light Foundation, Josephson Institute of Ethics (where he chaired the Character Counts entity), Aurora University, Uhlich Children's Advantage Network, and Interfaith Youth Corps (where he was the first board chair). He has also been very involved in his church. He is married to Sally; they have three sons and six grandchildren.

Sally Kinnamon graduated in sociology from Southern Methodist University. While still raising three small children, she returned to school and earned her RN and subsequently became a Nurse Practitioner. She worked as a case manager and trainer until her retirement. She took several specific courses to allow her to work part-time in a large metropolitan hospital as chaplain on the neurosurgical service. She also is involved in the FTD support group, acts as hospitality chair and is a member of the marketing committee at The Clare in Chicago, and participates in church activities. Sally, Ron and their three sons have lived in Dallas, Miami, Atlanta and San Francisco. They have retired in Chicago.

David L. Murrow is a graduate of Memphis State University and a former officer in the U.S. Navy. David built a respected career in the financial services industry. A leader in the development and deployment of strategic trading systems, he directs the day-to-day operations of several private trading platforms operating in multiple international markets. He was the primary caregiver for his wife, Linda, who died of behavioral variant FTD (bvFTD) in 2013. He is an active member of his local church, a member of the FTD Caregiver Support Group which meets in Phoenix and enjoys the opportunity to serve others who are struggling through the trials and tribulations associated with this difficult disease. David is the father of six children and the grandfather of nine.

James Noble, M.D., is Assistant Professor of Clinical Neurology in the Department of Neurology and the Taub Institute for Alzheimer's Disease and the Aging Brain at Columbia University. In 2009, Dr. Noble started "Arts & Minds," a non-profit organization offering cognitively and emotionally stimulating activities and art-centered experiences to persons and families living with Alzheimer's disease and related disorders. As a clinician in the memory disorders center at Columbia University Medical Center, he provides comprehensive dementia care which includes the patient and the entire family dynamic, particularly among disadvantaged communities.

Melanie Schulman, M.D., is a Clinical Associate Professor of Neurology and Psychiatry at NYU-Langone Medical Center. She earned her undergraduate degree from Harvard University, her master of philosophy degree from Cambridge University, and her medical degree from the University of Pennsylvania. She did her residency training at the Harvard-Longwood Neurological Training Program and her fellowship training in memory disorders at Boston University. She has been at NYU for many years pursuing behavioral/ cognitive neurology at the NYU Epilepsy Center, and more recently at the NYU Alzheimer's Disease Center and the Pearl Barlow Center for Treatment of Memory Disorders. Her research interests include

biomedical ethics (related to disclosure of biomarker information to subjects enrolled in aging studies), frontotemporal degeneration/progressive aphasias and clinical trials for treatment of neurodegenerative disease.

Matthew Sharp, M.S.S., joined the staff in December 2009 and is AFTD's Program Manager. Having earned his master of social service degree from Bryn Mawr College's Graduate School of Social Work and Social Research, he made a career transition to social services from the field of natural sciences. Matt also has a personal connection to FTD, as his father-in-law was recently diagnosed with the disease. Matt is integral to AFTD's patient and caregiver support and education efforts, and is responsible for development of AFTD's grassroots network.

Brett A. Steinberg, M.D., Ph.D., is a neuropsychologist who specializes in neurological and psychiatric disorders of adulthood, old age and adolescence. In addition to providing diagnostic and psychotherapeutic services to individuals, couples and families in a variety of outpatient and inpatient settings, Dr. Steinberg has served as a consultant to the New Haven Superior Court for Juvenile Matters and to the Learning Disabilities Association of Connecticut. As an investigator, he has conducted behavioral and functional neuroimaging research on age-related changes in brain structure and mental abilities, has studied the influence of concussion on cognitive processes, the effects of practice and premorbid cognitive ability on neuropsychological test scores and has explored factors that affect jurors' decision-making and retention of information presented at trial.

Nadine Tatton, Ph.D., joined AFTD as Scientific Director in June 2013. She has more than 20 years' experience as a neuroscientist in basic science and translational research combined with technology transfer and business development expertise. She has a personal connection to Amyotrophic Lateral Sclerosis (ALS), having been a family caregiver, and is deeply committed to the translation of scientific discoveries into treatment opportunities that will benefit patients and caregivers alike in FTD and other neurodegenerative disorders.

Eleanor Vaughan first heard of FTD eight years ago when her husband Richard was diagnosed with it. Since then she has taken everything she has learned as her husband's caregiver and shared it to help others caring for a loved with complicated and chronic or terminal diseases like FTD. In order to maximize Richard's abilities and maintain his overall well-being and functioning, Eleanor developed a structured daily routine based on his strength and weaknesses. She has since developed this approach into a formal caregiving curriculum and published it in the book "The Gift of Now," which she wrote with co-author Judith Pierson, Ed.D., Ph.D., a clinical psychologist who has worked with Eleanor in Delaware.

Connie Wasserman, LCSW, is the Associate Executive Director at the Sid Jacobson Jewish Community Center in East Hills, NY, where her many responsibilities include overseeing the development, implementation and administration of programs for cognitively and/or functionally impaired adults and seniors through the center's comprehensive Specialized Services Pillar. Over the course of her career as a clinical social worker, Connie has developed a variety of innovative services forseniors, adults and children including programming around the challenges of young-onset dementias like FTD.

Rebekah Wilson, M.S.W., is the Marketing Director for Arden Courts Memory Care Community in Farmington, CT. Rebekah holds a master's degree in social work and has served as a dementia consultant and speaker fornine years. Rebekah also has personal experience caring for a loved one with dementia. This personal experience drives her dedication to improving comfort and quality of life for those impacted by dementia and providing support for their care partners.

Dr. Edward (Ted) Huey

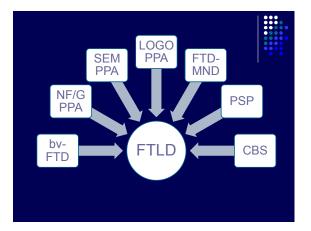
Frontotemporal degeneration (FTD)

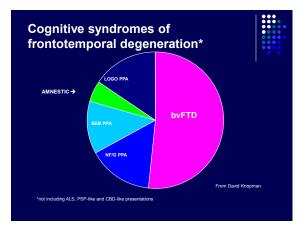
Edward (Ted) Huey, M.D. Herbert Irving Assistant Professor of Psychiatry and Neurology Taub Institute for Research on Alzheimer's Disease and the Aging Brain Columbia University

Overview

- Case reports
- Normal function of affected brain areas

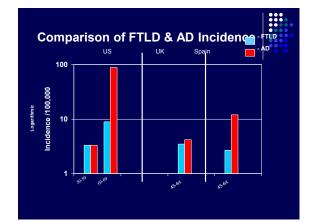
- FTD spectrum disorders
- Differential diagnosis
- Treatment
- Future directions

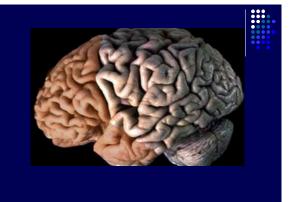




FTLD background

- 2nd most common cause of dementia in patients < 65 y.o.
- \bullet ~ 5-10% of all dementias





What do these brain areas do normally?

Normal functions of brain areas

• Frontal lobe

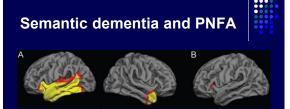
- Important for personality, higher cognitive functions, language production, how to perform complex activities, attention, motivation, emotional response, empathy, theory of mind
- Temporal lobe
 - Important for language comprehension, storage of knowledge about the attributes and characteristics of things

Symptoms of bv-FTD (Rascovsky et al. Brain 2011)

- Progressive deterioration of behavior and cognition
 - Behavioral disinhibition
 - Apathy
 - Loss of empathy
 - Perseverative or compulsive behaviors
 - Hyperorality and dietary changes
 - Neuropsychological profile c/w FTD

Primary Progressive Aphasias (language variant FTD)

- Nonfluent / agrammatic variant PPA
- Non-fluent (halting, effortful speech), poor grammar, drop-out of words
- Semantic variant PPA
 - Fluent speech, impaired naming and comprehension
- Logopenic PPA
- Word-finding difficulty, poor repetition, impaired "buffer" system

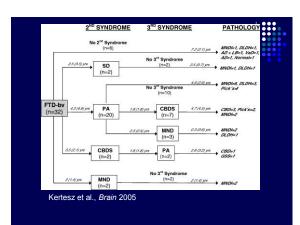


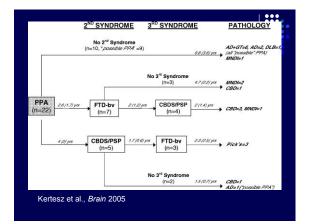
Rohrer et al, Neurology 2009

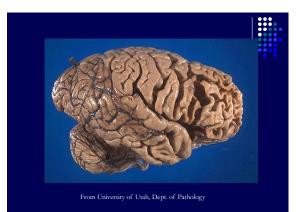
Related syndromes

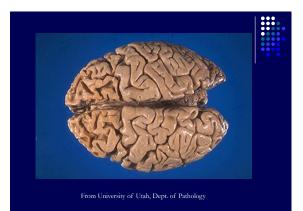
• <u>CBS</u>

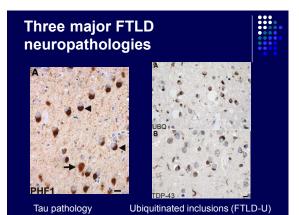
- Cortical:
- asymmetric apraxia and rigidity
- alien limb, cortical sensory loss, myoclonusBasal ganglia:
- bradykinesia
- increased resistance to passive movement
- <u>PSP</u>
 - vertical gaze palsy, axial dystonia, bradykinesia, rigidity, and falls

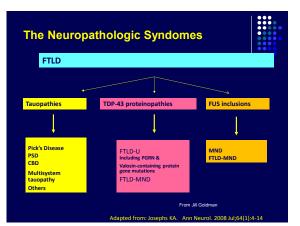












Differential diagnosis

• Patients with FTLD are often initially diagnosed with a different illness

- Psychiatric disorder
- Alzheimer's disease

Distinguishing FTD from AD

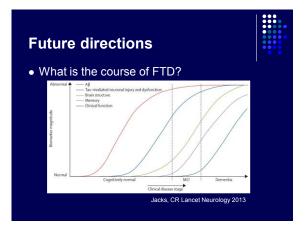
• Bv-FTD

Early changes in personality, behavior, social cognition, and executive function with relatively intact memory and visuospatial ability Motor symptoms

- Nonfluent/agrammatic variant PPA Relatively isolated to expressive aphasia
 - Aphasia and not word-finding difficulty
- Semantic variant primary progressive aphasia
- Episodic memory relatively intact Loss of semantic representation and not word-finding difficulty
- Frontal behavioral syndrome

Distinguishing FTLD from a psychiatric disorder

- Cognitive dysfunction, especially executive dysfunction
- Progressive course
- Motor symptoms
- Family history
- New onset of psychiatric disorder
- Distress and deficits in social cognition





- Oxytosin
- Select groups of FTD patients
- nimodipine for PGRN mutation carriers

Future directions, cont.



- Bringing together neurology and psychiatry
- Growing consensus that core constructs underlie psychiatric diagnoses. These constructs are more likely to be associated with neuroanatomical differences than traditional diagnoses.

Factor analyses of categorical psychiatric diagnoses (Kotov et al., Arch Gen Psych 2011)



- Internalizing (anxiety and eating disorders, major depressive disorder, and cluster C, borderline, and paranoid personality disorders)
- Externalizing (substance use disorders and antisocial personality disorders)
- <u>Thought disorder</u> (psychosis, mania, and cluster A personality disorders)
- <u>Somatoform</u> (somatoform disorders)
- <u>Antagonism</u> (cluster B and paranoid personality disorders)

Data reduction project

- Performed a factor analysis on the DSM diagnoses of 254 Vietnam Head Injury Subjects (55 controls and 199 with penetrating brain injury)
- Factor with eigenvalues > 1.0 and loadings >0.5 considered significant
- Partial correlations correcting for age, education, cognition, and overall lesion burden with defined regions of interest.

Factor analysis in VHIS study



- Internalizing (MDD, panic d/o, social phobia, PTSD)
- Externalizing (EtOH and substance abuse)
- Thought disorder (psychosis)

Anatomic associations

- Volume loss in the :
 - Left amygdala ↓ "Internalizing" (r=-0.174, p=0.027)
- Right lateral OFC ↓ "Externalizing" (r=-0.171, p=0.029)
- Right posterior cingulate cortex ↑ "Thought disorder" (r=0.151, p=0.046)

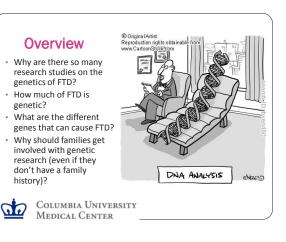
Areas associated with psychiatric factors. Blue (internalizing) L amygdala, pink (externalizing) R lateral OFC, yellow (thought d/o) R PCC

Advanced stage, severe impairment	Assessment of degree of assistance needed (e.g. possible out-of-home- placement or hospice referral); Discussion of genetic implications of neuropathological findings after autopsy	Consultations with cognitive rehabilitation professionals, physical therapists, speech therapists, and/or occupational therapists to enhance life participation and maintain functional abilities; Caregiver assistance and supervision to complete basic activities of daily living; Day programs for meaningful activity; Home health aides to help with patient self-care tasks and physical and safety needs; Referrals to residential facilities, palliative care and hospice when appropriate	ional, and online resources; rams to provide caregiver with avement support	Discussions to help family and patient plan for a peaceful death; Logistic and financial planning for death
Middle stage, moderate impairment	Continued assessment of symptoms; Assessment of degree of assistance needed (e.g., possible out-of-home- placement); Discussion of medication efficacy, side effects, and dosing adjustments as needed	Consultations with cognitive rehabilitation professionals, physical therapists, speech therapists, and/or occupational therapists to enhance life participation and maintain fu abilities; Caregiver assistance and supervision to complete basic activities of daily livi programs for meaningful activity; Home health aides to help with patient self-care tasks and physical and safety needs; Referrals to residential facilities, palliative care and hospice when appropriate	Introduction to educational materials and supportive local, national, and online resources; Home health aide or companion to assist caregiver; Day programs to provide caregiver with respite; Meetings with support groups; Emotion-focused coping strategies for grief and loss and bereavement support	Consultation with a social worker; Identification of suitable hospice and/or residential care facilities
Early stage, mild impairment	Diagnosis; Discussion of diagnosis and course of disease; Assessment of degree of assistance needed (e.g., home health aides); Assessment of burdensome symptoms and prescribing medications to manage them if necessary; Assessment for genetic testing and referral to a genetic counselor if warranted	Consultations with cognitive reha therapists, and/or occupational th abilities; Caregiver assistance ar programs for meaningful activity; Home health aides to help with p Referrals to residential facilities,	Introduction to educational materials a Home health aide or companion to as respite; Meetings with support groups; Emotion-focused coping strategies for	Identification of health-care proxy; Completion of power-of- attorney; Consultation with social worker regarding benefit eligibility
Aspect of multidisciplinary management	Physician responsibilities	Programmatic patient support	Caregiver support	Advance care planning

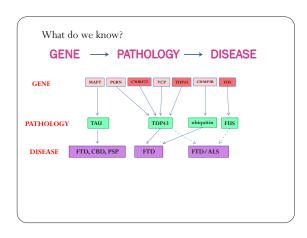
Domain	Symptom	Pharmacologic tx	Non-pharmacologic tx
Language symptoms	Expressive aphasia	None	Speech therapy; caregiver education; compensatory tools such as scripts and AACs
	Naming and comprehension deficits	None	Speech therapy; caregiver education on communication methods
Behavioral and neuropsychiatric symptoms	Apathy and inertia	None	Caregiver education and support; supervision and direction
	Agitation, aggression, and impulsive behaviors	Antidepressants, Atypical antipsychotics	Caregiver education; monitoring and removal of environmental triggers, caregiver oversight of physical and social environment
	Lack of empathy and sympathy	None	Caregiver education; caregiver support groups
	Perseverative and ritualistic behaviors	Antidepressants	Caregiver oversight; toleration of behavior; distraction
	Compulsive eating and dietary abnormalities	Antidepressants	Caregiver oversight of diet; environmental and physical modifications; consultation with dietician
Cognitive symptoms	Executive dysfunction	Evaluation for medications that could impair cognition	Consultation with cognitive rehabilitation therapist; compensatory tools
Motor symptoms	Falls	Evaluation for medications that could contribute to parkinsonism, orthostasis, or balance impairment	Environmental modifications; physical therapy; consultation with occupational therapist; walkers and/or wheelchairs
	Dystonia	Botulinum toxin injections	Splinting; physical therapy
	Parkinsonism	Carbidopa/levodopa trial (in part, for diagnostic purposes)	Caregiver support

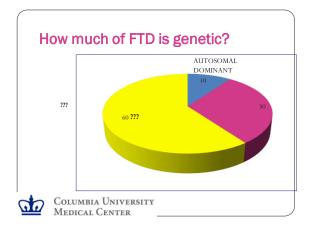
Hot Topics: The Importance of Genetics

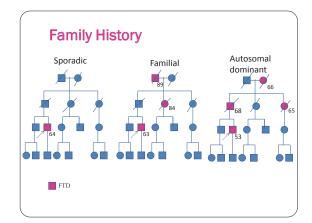


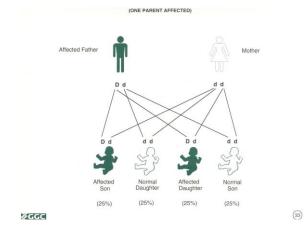


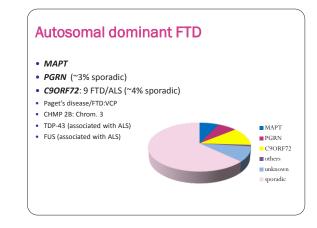








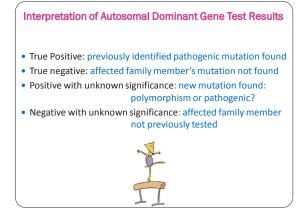


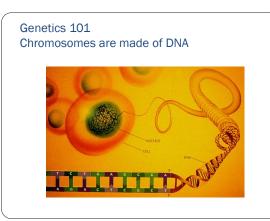


How do we know for sure if it's genetic?

- Must first test an affected person to determine a specific causal gene mutation
- THEN if an at-risk family member wants presymptomatic testing, they can ask for genetic counseling and then testing







Mutations

• Mistakes in the DNA sequence

e.g.

Normal gene: CATGAT Mutated gene: CAGGAT, CAGAT, CATTGAT, CATGATCATGAT

• Result of mutation: change in amino acid sequence of protein, hence change in function of protein OR inability to produce protein

Options for people at risk of hereditary dementia

- Genetic testing after identification of family mutation through blood or tissue
- DNA banking
- Genetic research study
- FTD Genetics Research with or without genetic results
- Autopsy

Importance of genetic research

- To understand mechanisms of disease
- Who can participate in genetic research?
 - Families with autosomal dominant family histories
 - Characterize features of mutations: spectrum of symptoms, biomarkers-imaging changes, CSF profile, etc.
 - Candidates for specific drug trials
 - Identify etiologies of mutational variation (other genetic markers or environment)
 - Sporadic families
 - Identify genetic or environmental risk factorsUnaffected family members
 - Controls





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

Genetics at Work Advancing FTD Research and Therapeutic Development

Nadine Tatton, PhD Scientific Director - AFTD





Genetics at Work – Advancing Research

It starts with you - the patient - the caregiver - the family

Patients and Families Donate Samples Fill out Surveys and Participate in Research Studies

 NACC-FTLD module (clinical, pathology)
 NY brain bank-Columbia Univ., Troxel brain bank-Mayo clinic, Northwestern Univ. brain bank for PPA/bvFTD

- FTD Stem Cell Consortium at Coriell Cell Repositories
 - Longitudinal research studies at FTD medical centers



Genetics at Work – Learning More About FTD Around the World

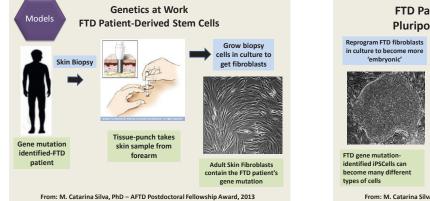
 Genetic screening of individuals and families will contribute to clinical trials based on familial FTD cohorts
 Screening increases our knowledge of FTD in other countries – the percentages of *C90RF72, MAPT,GRN* can vary by geographic region





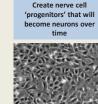
Genetics at Work

- FTD gene mutations can be introduced into the DNA of different animals (mice, fruit flies) or cells in culture to try and recreate the disease
- These animal and cell models allow us to learn about the biological pathways that contribute to FTD and test new drugs
- The newest model is the patient-derived stem cell, which allows us to study and test drugs in human autosomal dominant FTD cells in culture



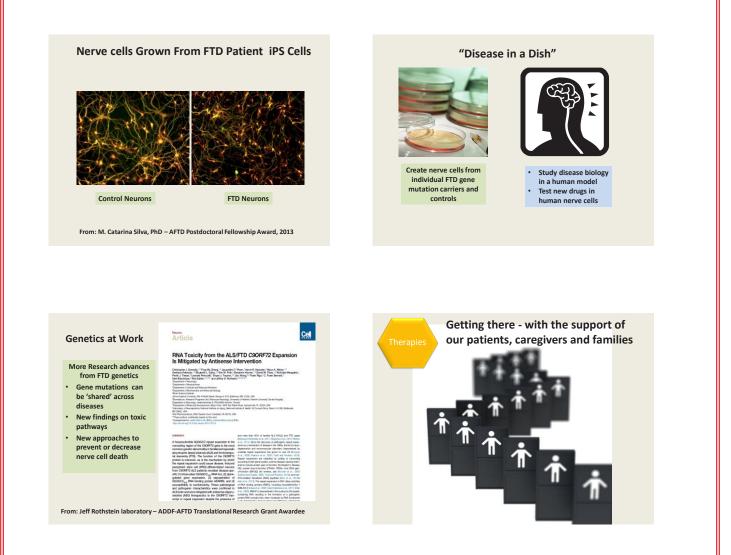
FTD Patient-Derived Induced Pluripotent Stem Cells (iPSCs)

Incubate in culture with special factors that can change IPS cells into brain, kidney, lung, liver or other cell types



Nerve cell progenitors contain FTD gene mutation

From: M. Catarina Silva, PhD – AFTD Postdoctoral Fellowship Award, 2013



Breakout: Framework for Moving Foward

Framework for Moving Forward

James Noble, M.D.; Eleanor Vaughan; Kerri Barthel, M.S.W.

Tasks to Consider as you Travel Along your FTD Journey Checklist

Learn About the Diagnosis

Confirm the diagnosis. A second opinion is recommended, when possible.

Learn about the diagnosis, symptoms and what you might expect.

Visit AFTD's website for information and resources: http://www.theaftd.org/support-resources/resources.

Register with AFTD and sign up for the newsletters: www.theaftd.org.

Start an FTD file of key articles and resources that will help educate others.

Share information with key family and friends.

If you have children or teens, get AFTD's booklet *What About the Kids*? Tell your kids about AFTD's website specifically geared towards kids and teens.

Contact AFTD's HelpLine with questions: 866-507-7222 or info@theaftd.org.

Build your Care Team

Identify and inform key professionals of your needs: neurologist, primary care physician, case manager/social worker and establish coordination.

Obtain copies of diagnostic evaluations for your records. Keep paperwork organized.

Keep a log or journal of significant changes in symptoms (positive and negative). Prioritize issues to address with doctor. Compile questions before each appointment.

Maintain chronological record of all medications started and discontinued.

Consult OT, PT and speech therapist for evaluation and techniques to maximize abilities.

Join an FTD caregiver support group. To learn if there is a group near you and to find out about phone groups, informal connections, and other options visit: **www.theaftd.org** or contact AFTD's Helpline 866-507-7222 or **info@theaftd.org**.

Explore peer support for the person with FTD. Visit: http://www.theaftd.org/support-resources/finding-support/support-for-patients.

Educate family, friends, and neighbors to help with understanding and acceptance. Notify your local police what is happening so they are aware and can be a support should a crisis occur.

Keep a list of what you need. Ask family, friends and neighbors to help.

Address Legal and Financial Issues

Consult an Elder Law Attorney. To locate an attorney near you go to: http://www.naela.org/Public.

Plan transition from employment, if still working.	
Apply for Social Security Disability (Compassionate Allowances Program). www.socialsecurity.gov/compassionateallowances	
Determine eligibility for Veterans Administration benefits. www.va.gov/healthbenefits.	
Complete legal documents (Power of Attorney, living will, will, etc.).	
Review financial and health care programs.	
Develop a Positive Daily Routine	
Follow a heart-healthy diet and get regular exercise.	
Stay active with friends and interests. Adapt activities according to strengths and needs.	
follow a regular daily routine to structure the day.	
Review and visit day programs and facilities in advance of possible placement.	
Jtilize professional counselors to help cope with changes.	
Apply for AFTD's respite grant. To obtain the simple application visit: http://www.theaftd.org/support-resources/finding-support/respite-day-programs	
Address Safety Issues	
Assess for safety and risk regularly and make changes as needed before a crisis occurs.	
Carry complete ID with emergency contact information. State that the person has a neurological lisorder. AFTD offers printable awareness cards online at www.theaftd.org.	
Keep home environment safe and equipped to reduce risk of falls.	
Where judgment is impaired, monitor bank accounts, investments and online activity.	
Jse GPS monitoring or similar device if there is any risk the person may get lost in the community.	
earn the laws where you live regarding driving privileges.	
Participate in Research	
follow emerging research to understand issues important in FTD.	
Become familiar with observational studies, clinical trials and opportunities to participate. To learn about current FTD clinical trials visit: www.clinicaltrials.gov.	
earn about role of brain autopsy to confirm diagnosis and advance research.	
Plan early if interested in brain autopsy/donation.	

Framework for Moving Forward on your Journey

The FTD Trek

- Many have visited multiple doctors and specialists before finally getting a diagnosis of FTD. A diagnosis can come as a relief and provides a starting point to begin planning for the future.
- FTD has unpredictable symptoms. There is no single course of progression for everyone which makes planning ahead more challenging.
- Although awareness and understanding is improving, be prepared to continue educating medical and non-medical professionals and advocating on your loved one's behalf.
- Speech therapy helps retain language longer for those diagnosed with PPA. A speech-language pathologist (SLP) can also help identify appropriate alternative communication strategies and devices.
- Physical/Occupational therapy (PT/OT) can help manage the physical symptoms of FTD. PT/OT can also help with loss of mobility and muscle control and provide guidance on tools and strategies to help address those issues.
- As a caregiver, remember it is the disease not the person you care about who may be saying mean things, treating you poorly, not listening, roaming away from the house, etc... As FTD progresses, the ability to think clearly and act rationally becomes impaired. Poor decisions or inappropriate actions are symptoms that the person cannot control. Try to be pro-active and prevent unsafe actions early and re-direct the behaviors towards something safer.
- Structuring the day for your loved one helps everyone. When possible, adapt their long term interests into modified activities that match the person's current functioning.
- Although your loved one with FTD can't change, you can adapt, be flexible and creative.
- If you haven't already, you will discover strengths you never knew you had!

The Road Less Traveled

- Although you may feel lonely and isolated, you are not alone! Others are facing the similar daily challenges that you are. Learn from one other. Find supports that meet your needs (FTD support groups, phone support groups, on-line groups, blogs, individual counseling, etc.).
- Know your limits; seek help from family, friends, and neighbors when needed.
- It is OK to ask for help. You cannot do everything 24/7.
- Don't forget to take care of your own physical, mental and emotional health.
- Take advantage of AFTD's Comstock caregiver respite grant program and give yourself a break.
- Reach out to your local Alzheimer's chapter. They may be able to suggest local FTD and/or early onset dementia resources and supports. Also, contact your local Area Agency on Aging.

Planning for the Path Ahead

- Address legal and financial issues early before your loved one's thinking and decision making abilities become impaired.
- Explore community services and residential services before you need them, a little research ahead of time can make transitions to care smoother for everyone.
- Consider participating in research. It will not only help advance the science of FTD, but can also provide access to specialized care and experts in the field.

Structure and Care - Eleanor's Curriculum Approach

I remember 2006 well. The year of Richard's diagnosis was the beginning of the "new normal" for us and as I devoured information about bvFTD, I realized that the doctor and hospital who gave us the diagnosis was "right on." How Richard did and our management of this disease depended on me, his caregiver, and how I could adapt because Richard's ability to adapt would decrease. After I recognized my honey's "inability to adapt", I realized that structure would help him not face the roadblock of figuring things out on the fly which is difficult for people with FTD.

I developed what I now call "the curriculum." I reached into the times in Richard's life that were joyous and successful and meshed them with his present abilities. I sought to make it not too challenging, yet challenging enough to keep him engaged and active. This led to the program he still uses. The structure includes six pieces of our lives that have always been important: nutrition, physical, emotional, intellectual, social, and spiritual. These six pieces are involved in his activities each day in some way that is successful for Richard. Examples include: reading for a half hour, exercising at the gym, swimming, and connecting with one of our children by phone each day.

The curriculum has been a benefit to me also. Knowing the routine helps me to structure some respite time into a day and helps me in my caregiving. Of course, the challenge to me is to adapt to the progression of the disease and then change up the curriculum. It has to change on a regular basis. Also, if we travel, we keep things as close to the routine as possible. Richard is able to express that the structure helps him greatly with confusion and calms him knowing what each day holds. The calm helps tremendously with this disease because as you know, there can be some obstinate behavior. Since the curriculum is written down, he can see it and refer to it and keeps me out of the loop of mood swings from the disease. I like to call the routine my "managed chaos." I have also learned that educating anyone involved with Richard is a great help to him and to me – thus I have developed a "Circle of Care."

Your Circle of Care is really several circles. Your first circle is family. Our first task was a family meeting where our family (and we are blended family) were educated and then some roles were established. I am the manager of this team and each person has a place on it. I text one of my team member every other day and that person is the day's "communicator." That daughter texts all others as to Poppa Bear's (which is what they call him) condition (good day, bad days, Mom needs help). We have a "visiting manager" – a daughter sets up a visiting schedule so the pace and number of visitors isn't too much. We have a "medical accompaniment," a daughter who goes on doctor visits with us and takes notes. We have a "Mom's fun" daughter who takes me out, challenges me to take care of myself. We have Dad's pal son…they golf, go to ballgames, give Mom respite. The grandkids are phone call pals. This works well to keep all involved and yet not burden anyone.

Your second circle of care is your friends (for us, primarily our church group as Richard is in Knights of Columbus). I educated these men and on Thursday they take Richard to lunch and to a movie. They also give him "jobs" to do which creates that feeling of being involved for him. Your third circle of care is your neighbors. Again education is so important. Our neighbors watch when Richard is trying to do something around the yard, take trash out. The Circle of Care knows that dignity is the main ingredient in giving their gifts of love. I started out on this journey thinking I could do it all (female syndrome and catholic school syndrome) and know that this is really selfish thinking and not good for my health. Asking for help was a gift to me and to others. Give love a chance.

Breakout: Understanding and Coping with Language Changes

Understanding and Coping with Language Changes

Melanie Shulman, M.D.; Ellayne S. Ganzfried, M.S., CCC-SLP; Ron and Sally Kinnamon

What is Aphasia?

- Aphasia is an acquired communication disorder that results from damage to portions of the brain that are responsible for language
- In the vast majority of people, these areas are on the left side of the brain
- The disorder impairs the expression and understanding of language as well as reading and writing
- Aphasia does NOT affect intelligence.

What causes Aphasia?

Sudden Onset	Slow Onset
-Stroke	-Neurodegenerative disease (Primary Progressive Aphasia)
-Traumatic brain injury	-Tumor
-Infection	-Infection

What Types of Aphasia are there?

FLUENT/ RECEPTIVE (Wernicke-type)

- Typically resulting from damage to the temporal lobe
- People with Wernicke-type aphasias speak in long sentences that have no meaning, add unnecessary words, create made-up words.
- Often these patients have great difficulty understanding speech and are unaware of their mistakes

NON-FLUENT/ EXPRESSIVE (Broca-type)

- Typically resulting from damage to the frontal lobe
- People with Broca-type aphasias speak in short phrases, requiring great effort
- They often leave out small words such as "and," "the," "is"
- Often these patients understand speech quite well, are often aware of their difficulties, and become easily frustrated

Primary Progressive Aphasia (PPA)

The diagnosis is made in any patient in whom language impairment **(aphasia**) caused by a neurodegenerative disease **(progressive)** constitutes the most important aspect of the clinical picture **(primary)**.

- Varied language patterns in PPA
- These language disorders are heterogeneous
- Some are fluent, others not
- Some with comprehension deficits, others not

Three clinical subtypes of PPA

1. Agrammatic/Nonfluent – problem with word order and word production. Also known as Progressive Nonfluent Aphasia (PFNA)

Speech is effortful and reduced in quantity. Sentences become gradually shorter and word-finding hesitations more frequent – almost stuttering. Word order may be abnormal or used in the reverse sense ("yes" for "no.") Word understanding is preserved, but comprehension, especially of lengthy or complex sentences, may become impaired.

2. Semantic – problem with understanding of words.

The person seems to have forgotten the names of common objects. Main feature is loss of word meaning, even of common words. While speech remains fluent, it loses many nouns, or "content" words, and therefore can sound empty of meaning.

3. Logopenic –problem with word-finding.

Interruptions of fluency due to frequent word-finding pauses but relatively intact syntax and word comprehension.

PPAs break the aphasia fluent/nonfluent "rule book"

- The dysarthria, almost universally present in Broca's non-fluent aphasias due to CVA, is rarely present
- The comprehension deficits, the hallmark of Wernicke's fluent aphasias due to CVA, are relatively mild
- Logopenia, or intermittent dysfluency, is common in PPA (whereby the patient is fluent when engaged in conversational "small talk," but markedly nonfluent when responding to directed questioning)
- In some patients, the ability to write language may be less impaired than the ability to speak (rarely the case due to CVA)

Heterogeneous progression of PPA

As the disease progresses, PPA patients may develop memory disorders, associative agnosias, personality changes, motor neuron disease, or asymmetric extra-pyramidal deficits – emphasizing the lack of rigid boundaries in these neurodegenerative syndromes.

Neuroimaging

- A wide network of brain regions including the whole L perisylvian region, L anterior temporal lobes bilaterally (L>R), and basal ganglia bilaterally were found to be atrophied in all PPA pts evident on structural brain imaging (MRI).
- PET scan imaging can be helpful in distinguishing subtypes of aphasia:

NFPA -- inferior frontal and insular atrophy Semantic Dementia -- anterior temporal atrophy Logopenic -- L posterior temporal cortex and inferior parietal lobule

Neuropathology

- Atrophy tends to be mostly in the perisylvian region in the agrammatic/ nonfluent and logopenic variants but extends into anterior and medial temporal cortex in the semantic variant.
- 60-70% of PPA patients demonstrate FTLD subtypes, and approximately 20% demonstrate the typical plaques and tangles of AD
- The FTLD pathology may include focal neuronal loss, gliosis, tauopathy, ubiquinopathy with TDP-43 proteinopathy (known as FTLD-U), and superficial vacuolation.
- Unknown: In the PPA-AD cases, why does the plaque/tangle pathology, known to cause the greatest initial neuronal loss in entorhinal and hippocampal areas, seemingly affect other distinct brain regions, accounting for the "aphasia without amnesia" pattern.

Genetics

- In non-familial cases, the agrammatic/ nonfluent variant (PNFA) seems more closely associated with tauopathy whereas the semantic variant may be more closely associated with TDP-43.
- The vast majority of cases of PPA are sporadic, but familial cases have also been linked to FTLD pathology and mutations in the progranulin gene.
- In contrast to the sporadic cases, the familial cases display an association of with the agrammatic/nonfluent FTLD variant rather than the semantic variant of PPA.
- In some of the progranulin mutation families, affected members display phenotypical homogeneity for PPA; whereas in others, some members have PPA and in others, the behavioral variant of FTD.
- The frequency of learning disabilities, especially dyslexia, is higher in PPA families than in controls or typical AD.
- The cellular mechanisms that make the same mutation lead to bv-FTD and others manifest PPA is unknown but the possibility exists that, in some patients, selective vulnerability of the language network might be genetically determined.

Treatments

- Small controlled trial with bromocriptine was negative
- Memantine versus placebo trial nearing completion
- Anecdotal reports with cholinesterase inhibitors are mainly negative (one small study showed a marginal benefit with galantamine)
- Transcranial magnetic stimulation presently being studied and results look hopeful.

Speech/Language Pathology Evaluation is essential component of clinical diagnosis of PPA. It should include:

- Assessment of different language modalities and components: speech, repetition, comprehension, reading, writing, phonology, syntax, semantics
- Assessment of functional communication skills for different settings and needs and for planning treatment strategy
- Client/family education and support

Need to understand the progressive nature of the speech-language impairments:

- Unlike stroke, in PPA, speech-language abilities gradually decline
- Initially, communication difficulties are the only cause of limitation to activities of daily living
- Ultimately, concomitant cognitive and motor difficulties develop

The Goal of Speech-Language Treatment is Functional Communication:

- Maximize communication at each stage of the illness
- Consider each individual in the context of their environment and communication demands
- Tailor treatment approach to current level of functioning with understanding of likely progression
- Address the symptoms –different for each variant
- Staged treatment approach, i.e., assess- treat-assess-treat
- Determine appropriateness for high-tech augmentative and alternative communication devices (AAC)
- Implement communication strategies and tools before they are needed
- Consider groups throughout the continuum

Communication Supports:

Unaided (Natural Approaches)	Aided (Low-Tech and High-Tech Options)
Vocalization	Paper and pencil
Gestures	Communication Books/ Wallets
Eye gaze	Communication Boards/Cards
Body language	Speaking Computers
Sign language	Mobile Technologies
Communication Partner Training	Speech Generating Devices

Tips for the Supportive Communication Partner

- Manage environment
- Manage your feelings, language, thoughts
- Have realistic expectations based on communication strengths and areas of difficulty
- Provide choices
- Take and use pictures
- Set up a way to "come back to it later"
- Be patient-Count to 10 in your head before requiring a response
- "Change the channel"
- Verify understanding
- Create scripts/ core set of relevant words and phrases
- Use any and all modality, i.e., writing, drawing, speaking, gesture, facial expressions

Resources

www.aphasia.org

www.theaftd.org

<u>www.reknewprojects.org</u> -> Primary Progressive Aphasia -> Communication supports

Cognitive Neurology and Alzheimer's Disease Center (CNADC) of the Northwestern University Feinberg School of Medicine <u>www.brain.northwestern.edu</u>

National Institute on Aging <u>www.nia.nih.gov/alzheimers</u>

http://memory.ucsf.edu

www.aphasiasoftwarefinder.org

Session Presenters

Melanie Shulman, M.D. Associate Director, Cognitive and Behavioral Neurology Pearl Barlow Center for Memory Evaluation and Treatment Associate Leader, NYU Alzheimer Disease Center Clinical Core NYU Langone Medical Center, Comprehensive Center on Brain Aging melanie.shulman@nyumc.org

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Ron and Sally Kinnamon Family living with PPA <u>skinnamon@icloud.com</u>

Acknowledgement to Sandra Weintraub, Ph.D., Melanie Fried-Oken, Ph.D., CCC-SLP, and Maya Henry, Ph.D., CCC-SLP for contributing to this information.

FOR A STRATEGY TO WORK THERE MUST BE AGREEMENT BETWEEN THE PARTIES AS TO ITS VALUES AND ITS UTILIZATION

COMMUNICATION STRATEGIES FOR PPA

Speech therapy	Communication wallet	Notebook and pencil
iPhone, iPad synced	Calm, quiet environment	Few distractions
Short, simple sentences	Speak slowly	Repeat as needed
Agree on when to offer help	Digital watch	Allow processing time

LIFE STRATEGIES FOR PPA

TELL people	Self-care (you are a gift)	Medic-Alert bracelets
Exercise	Socialize	Support group
Plan where/how to live	Get legal things in order	Laugh
Focus on abilities	Time alone for both	Do for others

Find joy and celebrate

"TRUTHS" WE HAVE DISCOVERED

This whole process is unpredictable

Role reversal

Always a little behind in developing new strategies

Both have losses, and both are grieving

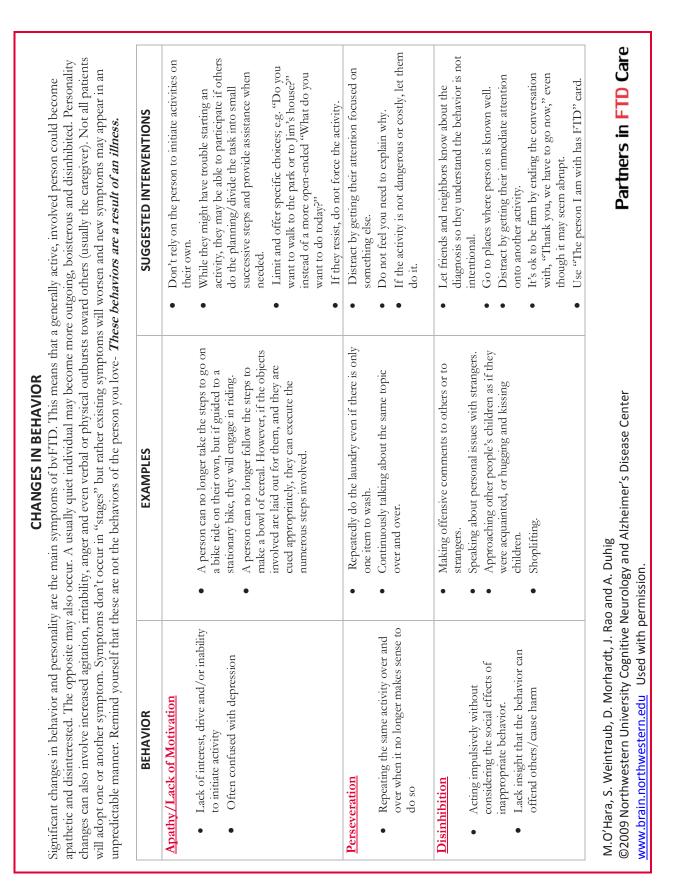
Forgetfulness vs. inability to process conversation

Loss of autonomy is difficult

There will be misunderstandings

Must work at not being "joined at the hip"

Breakout: Understanding and Coping with Behavior Changes



Partners in FTD Care	and A. Duhig urology and Alzheimer's Disease Center mission.	M.O'Hara, S. Weintraub, D. Morhardt, J. Rao and A. Duhig © 2009 Northwestern University Cognitive Neurology and Alzheimer's Disease Center www.brain.northwestern.edu Used with permission.
 If it is safe, accept the behavior and arrange for necessary supervision. If unsafe (scratching at a sore until it bleeds), consult with a physician to consider medications that can minimize compulsive behaviors. 	 Person needs to continuously walk on the same route for 2 hours every day at 2pm. Continuous whistling, drumming fingers in certain patterns. Rigidity and inflexibility, and insistence on having his or her own way, increasing difficulty adapting to new or changing circumstances. 	Ritualistic/Compulsive Behaviors Acts that are completed over and over again, without purpose and unrelated to the circumstances in which they occur
 Provide supervision while cating, setting out portions. If necessary, lock up foods and keep raw foods out of sight. Use distraction. 	 Taking food from someone else's plate at a dinner table. Gorging on food to the point of vomiting. Eating anything in sight with no consideration to how much eaten. Eating uncooked meat from the fridge. Eating only a certain type of cookie. 	 Hyperorality Compulsive cating Craving carbohydrates or sweets and no ability to regulate intake or "feel full"
 Determine if the behavior is putting the person or others at risk. If so, distract with other objects that get the person's attention immediately, such as calling them on a cell phone to interrupt an activity-the person is likely to answer it because that is automatic behavior. Note that calling their name may not work to get their immediate attention. 	 Seems to be drawn to objects or actions in the immediate environment (e.g., picks up objects that are part of others' activities, seems to imitate other others' behaviors) even when those objects or actions are not purposeful or appropriate for the moment. Picking up the phone when walking by it even if it is not ringing or there is no intention of making a call. 	 Utilization Behavior Difficulty resisting impulses to operate or manipulate objects that are within reach "Automatic" behavior, the kind of action we have all experienced when an elevator door opens and you automatically exit despite the fact that it is the wrong floor
 Although it is very difficult, <i>do not take this personally.</i> Find emotional support and companionship from other friends/family or support group. Seek professional counseling. Let others know about the diagnosis so they are not offended. 	 Seems to withdraw in familiar company. Displays emotions that are inappropriate- e.g, laughing at a funeral. Seems to "not care" about other's distress. Seems indifferent to spouse with a diagnosis of cancer. 	 Lack of Empathy/Emotional Changes Showing no emotions- seeming flat and disinterested Showing exaggerated jocular or improper emotions. A lack of sympathy or compassion to others' distress

Aggression		
• Because many individuals with FTD are not aware of their illness, they may become frustrated at limitations and constraints that they do not understand and consider to be unfair and punitive. As a result, the person may occasionally strike out at the caregiver or resist assistance.	 Shouting, name-calling or physical abuse (hitting, pushing). These behaviors can occur suddenly, with no apparent reason, or can result from a frustrating situation. 	 Stay out of the person's way if they are combative. In extreme cases, call police but explain the person with FTD's condition. Never point out the problem to the person, try to reason about their behavior, or argue about the "logical" solution.
Reasoning		• Do not argue. No amount of reasoning will make the person able to grasp the ideas.
 Not able to categorize information or think in the abstract; very literal interpretations Lacks flexibility in thinking and unable to pursue an alternative solution if the first one doesn't work May increase safety risk since they 	 Person cannot understand explanations about their own illness and is resistant to continued attempts to make things clear. May behave as if the caregiver is "bossy" or unreasonable or trying to control them. Cannot reason logically about the solutions to simple problems (e.g., how to respond in the 	
have difficulty recognizing consequences of behavior	event of a fire).	 Make sure that all legal steps have been taken to protect the person and obtain power of attorney so that decision-making is not left to the person with significant reasoning deficits.
 General Communication Tips Always avoid confrontation. This e Try not to take the person's behav When it's helpful for the person, k 	Always avoid confrontation. This can be done by not arguing or trying to point out the truth. Try not to take the person's behavior personally. There is no intent to hurt but only the inability to have normal reactions and feelings. When it's helpful for the person, keep decision making to a minimum. Don't put the person in a situation that stresses failing reasoning	truth. 2 inability to have normal reactions and feelings. 2 erson in a situation that stresses failing reasoning
 capacity. Approach the person with a calm, reassuring emotional expressions than negative ones. S caregiver's emotional facial expression can e showing imitative behavior. But a smile will 	capacity. Approach the person with a calm, reassuring tone. Smile. Individuals with frontotemporal dementia are better at understanding positive emotional expressions than negative ones. So if you are frowning or looking sad or angry, the person may not understand. Alternatively, the caregiver's emotional facial expression can elicit the exact same expression in the patient even though the patient is not feeling that way but showing imitative behavior. But a smile will elicit a more positive response.	capacity. Approach the person with a calm, reassuring tone. Smile. Individuals with frontotemporal dementia are better at understanding positive emotional expressions than negative ones. So if you are frowning or looking sad or angry, the person may not understand. Alternatively, the caregiver's emotional facial expression can elicit the exact same expression in the patient even though the patient is not feeling that way but is showing imitative behavior. But a smile will elicit a more positive response.
M.O'Hara, S. Weintraub, D. Morhardt, J. Rao and A. Duhig ©2009 Northwestern University Cognitive Neurology and Alzheimer's Disease Center <u>www.brain.northwestern.edu</u> Used with permission.	ao and A. Duhig Veurology and Alzheimer's Disease Center vermission.	Partners in FTD Care

	Meaningful Activities • Drovide materials that are readily available and not denoerous Tiosay muzzles drawing materials coins to be sorted Jaundry to be folded
	• The person should be provided with physical activities within their capacity. They may require support, such as a "trainer", an individual who can be hired to take the person out for a walk daily, but also to do other types of stimulating activities. Using such a label for getting the proper assistance the patient needs may be more acceptable to the patient than a "companion" or a "caretaker."
	When the individual with behavioral changes shows new symptoms, don't assume that it is the disease. Because patients find it increasingly difficult to articulate such things as pain or discomfort, they may manifest such things as agitation or irritability. It could be the disease or it could be something else that could be addressed with a visit to the primary care doctor. With all new behaviors that you observe, go through the following checklist to determine what is causing the change and find the most appropriate intervention:
	• Could this be a separate medical problem that is causing the change in behavior? For example, the person may have a toothache but be unable to articulate the precise problem. Another example is an imbalance of thyroid function or other chemical imbalance in the body that temporarily makes the dementia symptoms look a lot worse.
33	• Identify triggers of certain behaviors -Is the environment triggering the behavior? Although many behaviors are erratic and have no explanation or precedent, some may be reactions to certain types of situations. For example, the person becomes agitated when there are more than three people talking. If so, what in the environment can be changed? In this example, the solution might be to reduce the number of people the person interacts with at one time. Invite one adult child and the grandchildren to dinner instead of the whole family. Try to identify if there are triggers and what they might be.
	• Is this behavior safe for them ? Is this safe for me/others ? Some behaviors are very annoying but are not injurious to the person or others. On the other hand, if the person does not recognize that an 18-month old child cannot be left on the living room floor with the front door open and a flight of stairs not far away, precautions need to be taken to make sure that the person is not put in a situation where they cannot exercise judgment. Even though the patient may be able to play with the 18-month old in an appropriate way, they are unable to be left alone with the child in this instance.
	When to consider medications
	• Trying the above strategies is always the first step in responding to changing behaviors; however, sometimes medications can also help. Some serotonin reuptake inhibitors are often prescribed for carbohydrate craving, disinhibition and impulsivity. Persons who experience uncontrollable aggression or delusions are sometimes prescribed low doses of antipsychotic medications. It is important to consult with a specialist in this area such as a psychiatrist with expertise in dementia and pharmacology.
	M.O'Hara, S. Weintraub, D. Morhardt, J. Rao and A. Duhig ©2009 Northwestern University Cognitive Neurology and Alzheimer's Disease Center <u>www.brain.northwestern.edu</u> Used with permission.

Breakout: Comfort Care and End of Life Considerations

Comfort Care and End of Life Considerations:

Rebekah Wilson, M.S.W.; Brett A. Steinberg, Ph.D., ABPP; David Murrow

The Illness:

FTD represents 5 - 15% of dementia cases; second most common form of presenile dementia (onset before 65 years); family history in 25 - 50% of cases, often with autosomal dominant inheritance from one parent.

<u>Molecular Changes</u>: In last 6 - 7 years, researchers identified all common genetic mutations underlying FTD. Errors in gene sequences cause abnormal regulation of proteins in brain cells. Examples include GRN (gene for progranulin, a growth factor in many cells; in neurons, promotes formation of structural projections); and *C9ORF72* (chromosome 9 open reading frame 72; protein's function unknown, but abnormally large number of GGGGCC units may cause loss and/or gain of function.) Over time, mutations lead to abnormal protein accumulation in increasing numbers of cells.

<u>Cell Damage</u>: Most cases of FTD fall in three major pathological subtypes (FTLD-tau, FTLD-TDP, or FTLD-FUS) based on associated protein. One example is TDP-43 (protein that moves into and out of cell nucleus and that regulates RNA; involved in 50% of FTD and most ALS patients). Over time, abnormal protein accumulation results in dysfunction and/or structural damage in increasing numbers of cells.

<u>Brain Dysfunction</u>: In variants of FTD and related conditions, abnormal protein accumulation occurs in specific brain regions (e.g. brainstem, cerebellum, thalamus, and frontal, temporal, and parietal lobes); intrinsic functions of those regions, and roles they play in conjunction with each other, determine symptoms. Over time, dysfunction and/or structural damage in increasing numbers of cells leads to 'final common pathway' of dementia.

The Symptoms:

<u>Cognitive Deficits</u>: Frontal lobe = nonfluent aphasia; temporal lobe = semantic dementia.

<u>Emotional and Behavioral Changes</u>: Frontal lobe and insula = changes in social judgment and disinhibition; anterior temporal lobe = changes in eating.

<u>Motor Impairment</u>: Brainstem and extrapyramidal system = swallowing and balance problems.

Resources to consider:

Support groups, in home care, placement outside the home, hospice services For more information on hospice services for FTD see: http://www.theaftd.org/wp-content/uploads/2011/10/Hospice-and-FTD_Hospice-of-the-Valley-2011-ppt-online-version.pdf

End of life Considerations/Advanced Directives:

Antibiotics, CPR, Hospitalizations

Thoughts from the Journey - By: David Murrow

Making a Decision:

My wife, Linda, died of the ravages of bvFTD on April 15, 2013. While we went through the "disease process" fairly quickly - just two years, seven months and sixteen days from date of diagnosis to date of death - the early stages of the disease took many years to evolve.

This "evolution time" included month after month of unstable behavior, withdrawal, isolation, living in separate locations and finally divorce. By early 2010, as Linda's behavior became more and more bazaar, it became obvious that she could not go on alone. At her doctor's request I moved into her home and my care giving journey began.

I arrived on Linda's doorstep with a desire to help which was deeply clouded by the memories and feelings of anger and betrayal that had been building for months, if not years. I wasn't sure I wanted to be there and I think Linda probably felt the same.

Several months into the search for an answer to what we were dealing with I read a small book titled; "<u>A Promise Kept</u>." It's was written by a man who details the project of caring for his wife through a similar set of circumstances. I was truly touched by his realization that this is not something he "had" to do, but something he "got" to do, and that realization turned my journey around.

So I made my decision...I don't **have** to do this, I **get** to do this! The feelings of resentment and anger just seemed to slip away - I **get** to do this! I **get** the privilege of helping someone I love, so very much, travel through the darkest days of her life. I **get** to be her guide, her helpmate, her advocate, her voice and her companion. I **get** to lift her up, moment by moment, and build the highest quality of life possible - each day...until the last day...WOW!

Sometimes we need to turn the "lenses" around in our minds. When we do we "see" it's not about "us" it's about "them" - and giving is always better than receiving!

Chickens and Pigs:

Ever have bacon and eggs for breakfast? I am sure we all have, some of us do it all the time. Ever consider the role the chicken and the pig played in providing your breakfast. I'll tell you what happened...the chicken was **involved** - but the pig was **committed**!

My worst days as a caregiver were "chicken" days; just involved and nothing more. My best days came from acting as the "pig"; totally committed to the process, dedicated to providing all Linda needed, without reservation or exception. I grew to love being a pig!

Pick a Theme Song:

I seem to function better when I have goals, a plan of attack, a strategic plan laid out before me. I love things like that. I like to develop what I call a "stump speech" - a short, quick summary of what I am trying to accomplish. If someone would only give you two minutes to explain your life's mission - what would you say?

My stump speech came from the words and thoughts contained in the first verse of a popular song recorded by the mother/daughter team known as "The Judds." The song is titled "Love Can Build A Bridge" and the words I used are these:

I'd gladly walk across the desert with no shoes upon my feet; To share with you the last bite of bread I had to eat. I would swim out to save you in your sea of broken dreams; When all your hopes are sinking, **Let Me Show You What Love Means**.

So that became my theme and a theme I shared with everyone involved with her care. Everyday, every moment focused on showing Linda what it meant to be loved. It's a pretty simple plan really, not always easy to do, but a simple plan nonetheless.

The Lone Ranger:

Don't try to do this alone...especially during the final or "end stages" of the disease. Make your support team as broad and deep as you possibly can.

I was certain that nobody could care for Linda better than I could. And do you know what, I was right! But what I soon learned was that scores and scores of people could take care of her just as well as I did - and it was good for me and, more importantly, it was good for her when I let them help.

And oh by the way, "keep the door open." People want to help but they often hesitate because they don't know what to do. Folks who can't or won't help during the process will often want to visit at the end, just to say goodbye. That's ok, they're just trying to get through this like the rest of us.

Don't Chase The Sunset:

I had a constant sense that the sun was setting on us - certainly on Linda - but on my life as well. I felt as though I was always running, trying to stay in the sunlight - to somehow avoid the setting of the sun. If I could just stay in the sunlight I would be alright - so my goal became avoiding the darkness.

But I recall reading a book about grief wherein the author described similar feelings and explained how he had come to the realization that the quickest way to the sunrise is to stop the vain, futile race to keep up with the light and instead, turn around and run into the darkness.

So that's what I did. I studied the disease process, read books about care giving and dedicated myself to understanding the journey we were going through. I failed terribly time and time again, but the advice was sound..."run into the darkness"...before you know it you'll find the warmth of the sunrise.

Migrations:

I've been known to challenge folks, from time to time, so here's yours...Take a 3" by 5" card and on the front side write down the best things that ever happened to you. On the back write down the worst things to ever happen. If you're like me, having a loved one with FTD is somewhere in the center of the back side, often written in all caps and bold print!

Now imagine having a small stick or handle on each side of the card, and visualize yourself spinning the card around and around. The spinning of the card represents the passage of time and your reflection on what each event, written on both sides of the card, really means.

If you're at all like me, you'll find that over time many of the events you've written down will have migrated to the other side of the card. Many of the "best" things are now on the "worst" side and many of the "worst" are now considered to be the "best." Some of the events you have listed on one side or the other will now be on both sides...go figure!

What does it all mean? Some days I am not sure I know. What I think it means is that God has a plan for each of us, and in this sovereign plan He is showing us that He uses the painful, difficult experiences of life for our ultimate good. And He knows, as well, that many of the things we strive for, day after day, are really worthless - without lasting value - and should have been on the back side of the card all along.

Breakout: Making a New Life After Being Diagnosed

Making a New Life after Being Diagnosed

Howard Glick, Sharon Denny, Matt Sharp and Stephanie Cosentino

"Just because your condition worsens, doesn't mean your life is over. You just need to adapt and work around whatever symptoms and complications get in your way. You've a right to live a life with happiness and purpose." --Howard Glick

Suggestions for You and Your Family

Accept the diagnosis. That is what lets you begin to adapt and rebuild and go on living.

Learn about your diagnosis. Gather information and resources for yourself and to give to others.

Mourn the losses. Acknowledge the changes as you become unable to do as many things. Express the sadness and then refocus on what you can still do.

Think of the symptoms as disabilities. Develop strategies to adapt and manage the symptoms as you would a physical disability. Find a different way to do what you need to or want to do.

Create a team of family, friends, and professionals who you trust to help you as your needs change.

Plan ahead. Complete your powers of attorney, advance health care directives and will right away so you have the greatest say possible in these legal matters.

Develop a routine. One of the big adjustments is the loss of a career or regular daily structure. Think about new ways to use your experience. Maybe mentor others in a lower stress environment, or volunteer with an organization or cause you support. Do things you like and stay connected to friends.

Build healthy eating, exercise, and sleep into your routine. A heart-healthy diet and regular exercise have many general health benefits. Try meditation, yoga or other techniques to manage stress.

Find support. Options are increasing to find other people with FTD and early stage dementia for support. See the Resources section below.

Be practical. Let others help you with medical appointments, meals and household tasks, finances and paperwork, transportation and companionship.

Pick your battles. Not everyone will understand FTD or the effect it has on your life. Some people you think you can count on will disappoint you. Invest energy in those who listen and try to help.

Get involved. Your experiences and voice matter. Let family, local providers and AFTD know if you would like to work for awareness or advocate for improved services. They can help you to find the right opportunity.

Participate in research. Volunteers are needed for research studies to advance scientists understanding of the diseases and to a cure. If you are able to participate, this is a wonderful way to contribute to a better future.

What We Can Do Now to Improve Quality of Life for People with FTD

Explore what people with FTD and related dementias say about their experience

- "Our Side of the Fence" A recorded presentation by four people with early stage dementia discussing their experiences. <u>http://www.youtube.com/watch?v=s7-LPkU4jqM&feature=youtu.be</u>
- Creating Life with Words: Inspiration, Love and Truth by Kate Swaffer http://kateswaffer.com/dementia/
- The FTD/Dementia Support Blog by Howard Glick
 <u>http://earlydementiasupport.blogspot.com/</u>
- Ask the FTD Patients. A closed questions only Facebook group for those who want the patient's perspective on questions about FTD. This is not a support group. All questions are screened by group administrators before posting.

Organize a small gathering for people diagnosed with FTD to meet each other.

People with FTD disorders rarely have the opportunity to meet others who are also diagnosed. Increasingly, caregiver groups, service providers and individuals bring people with FTD together for informal support.

Address changing relationships.

Interpersonal relationships are changed by FTD and other dementias. The adjustments are challenging for the person with FTD and their caregiver or family in different ways. Open communication and patience are needed to create new relationships.

"It would seem to me, if you want people to succumb to dementia quicker

than they normally would you should think for us, instead of letting us think for ourselves.

If you want our brain to stop working then help us to stop using it"

-Kate Swaffer

Not all people diagnosed with FTD have a specific caregiver to turn to.

FTD affects many single people who manage the disease alone as long as they can. Creative systems and supports are needed.

Increase awareness efforts of FTD and that not all dementia is Alzheimer's disease.

Advocate for public policy, services, systems and supports that are responsive to the needs of people with FTD.

Advocate for increased research funding for FTD and related dementias.

In the Words of Those with FTD: Diagnosis, Denial, and the Value of Support

(Quotes compiled from multiple contributors to online and telephone support groups)

"When first diagnosed my doctor didn't think I would live more than 1-2 years. Here it is 4 years later and I'm still here. Enjoy what you have and try to focus on the positive and the difference you can make by making this disease known. We can still have a quality of life and make an impact on other people."

"A friend I met after my diagnosis said, 'you seem fine to me. So now you're down at our level.' It's not about levels; it's about functioning, setting goals and reaching them, looking towards the future and reaching it with success and having a blast along the way. It's about knowing who I am and living it consistently day after day."

"Ultimately that is what this group is for....to ask and find out, compare etc. Since it is a private group we should all feel free to just put it all out there. No shame. That way we all get informed or have knowledge of what's lying ahead for all of us that are on this same crappy team."

"I don't have behavior issues yet, but when you do something 'unusual' like getting lost in your neighborhood or putting plates in the freezer, are you aware at all of what you're doing? Since so many of you write about it, I wonder are you aware of when it happens or does someone tell you about it after it happens?"

"I think a bit of doubt hangs forever. Best just to make the best life you can now. Told a close friend a few weeks ago I felt pretty normal and was thinking of maybe going back to work. She looked at me like I was crazy. I then started thinking about my life and behavior. Slowly losing your mind with no pain is incredibly deceptive. No pain to confirm a definite problem.

"I love that I could FINALLY say that out loud here when I've kept it inside in the real world. And I love that you guys know what I'm saying and you feel it too. THANK YOU"

"I truly believe it is good to get these feelings out. I don't think we stay there all the time but IT does come up. I cannot be a Pollyanna and Susi Sunshine. I try to keep a positive attitude and not be Negative Nettie with the few friends & family I am with. You and I need to be able to say, 'Dammit I am mad' -- and be understood. It is what we are dealing with. Then we can present a better face to those who don't get it."

"I wish I had some sense of hope that I was misdiagnosed, but I seem to be a textbook case. When I think of the life I had and the way I am now I don't feel there is any room for doubt. I am trying to get into clinical trials so that I can feel my life has some meaning. Even if it doesn't bring about treatment in my lifetime, if it can help the next generation then I will feel like I have accomplished something."

"You put into words what I have been feeling...I often feel that the neuro misdiagnosed me...but my family says no he is right...I feel pretty good and I am still working...this fear of FTD is with me 24-7 and it is very upsetting...waiting for the other shoe to drop...anyway I have been inspired by Howard and I keep going....2 of the people I work with know of the diagnosis and they both say it can't be right...oh well."

"When I went to get tested, I was terrified that they would say I had Alzheimer's. My kids were so relieved to learn it was FTD. (They didn't know what FTD was right then.) But this is what I keep quiet - I was equally terrified they would say everything was fine and then I'd have no answer about why I was struggling so much."

"So then we have to keep moving forward and not think about it...it is easier said than done..."

"YES!!! Okay....here we go, moving forward, denial stripped away, eyes wide open, looking to the future as it is and enjoying every moment we can and forgetting whatever gets forgotten. It's kind of empowering.....or freeing."

Resources

Face-to-Face Support

- Younger-onset or early-stage dementia support groups. These can help you to accept the diagnosis, adapt and keep living. Check with the local Alzheimer's Association or memory care center for groups in your area.
- Informal get-togethers. Some FTD caregiver groups have started ways for the people diagnosed with FTD to meet informally with each other for support. FTD caregiver groups are listed on AFTDs website: http://www.theaftd.org/support-resources/finding-support

Online Support

- FTD Patient Support Group on Facebook, private group facilitated by Howard Glick. Contact him for more info: <u>howardjglick@gmail.com</u>
- A Meeting of the Minds connects people diagnosed with dementia and others who are meeting the challenges of dementia. <u>http://minds-meeting.com/about</u>
- Primary Progressive Aphasia Group on Facebook, private group facilitated by Natasha Young.
- The FTD Support Forum offers online support for caregivers and patients http://ftdsupportforum.com

Telephone support group

• AFTD Telephone Support Group for People with FTD Contact <u>info@theaftd.org</u> or 866-507-7222 for more information

AFTD website and HelpLine for information and questions

Helpline – 866-507-7222 or info@theaftd.org Register for newsletters and announcements – <u>www.theaftd.org</u> *It Is What It Is* – film to promote awareness

Awareness cards (from AFTD)



Medic alert bracelet or chain



AFTD Resources

*******NEW! ******* AFTD Kids and Teens Website - Explore. Learn. Connect.

This exciting new website with separate sections for young children and teens provides reliable information and empowering coping strategies for children who have a parent or other close relative affected by FTD. Visit: www.AFTDkidsandteens.org

AFTD Website

The place for information, resources or support related to FTD. The Healthcare Professional section now includes material on clinical criteria, diagnosis and treatment and archived webinar presentations. Visit: www.theaftd.org

AFTD HelpLine

AFTD's most important direct service to patients, caregivers and professionals. The HelpLine is staffed Monday - Friday during office hours. Contact: 866.507.7222 toll-free or info@theaftd.org

A Guide for Managing a New Diagnosis

"The Doctor Thinks It's FTD. Now What?" is a publication from AFTD that provides guidance for individuals and families facing a diagnosis of FTD.

Caregiver Respite Grants

The Comstock Caregiver Respite Program encourages family caregivers to reenergize through the use of respite services. The program provides \$500 grants to eligible caregivers.

Connect with Support

AFTD connects people with FTD and caregivers with support that fits their needs. Visit the website for a listing of local FTD groups by region. AFTD provides telephone support groups and individual connections when no local group is available.

"It Is What It Is" (DVD)

A powerful, short documentary that features four families as they confront FTD. The DVD introduces people to the disease and its impact. Excellent for raising awareness and helping others understand the needs of people with FTD and their families.

The Gateway

The Gateway is AFTD's bimonthly electronic newsletter for caregivers. Each issue provides information about what's happening at AFTD, encouragement for caregivers and research updates.

Visit AFTD's website for more information on these and the growing array of resources available for people with FTD, families and professionals.







Partners in **FTD Care**

Education and Support for Community Care Providers

Frontotemporal degeneration (FTD) is a disease process that causes changes in behavior and personality, language and/or motor skills. It accounts for 10-20% of all dementias and is nearly as common as Alzheimer's disease in people under age 65. **The symptoms of FTD differ significantly** from more common forms of dementia. **Partners in FTD Care** helps home health, day program, facility care and rehabilitation therapy providers gain the knowledge and confidence to serve people with FTD and their families.

Partners in FTD Care is an education initiative of the Association for Frontotemporal Degeneration that brings together health professionals, experts and families to promote understanding of FTD and to develop best practices in community care.

An Introduction to FTD

Visit the Healthcare Professionals Section on AFTD's website for clinical criteria and information on treatment, interventions and the Partners in FTD Care initiative.

Training materials include:

- **AFTD's powerful film,** *"It Is What It Is"* introduces FTD and the challenges that patients and families face. The DVD comes with a 12-page information booklet, discussion questions to use with staff and leader's version for trainers.
- **Clinical case studies** developed by experts to highlight different presentations of FTD and interventions; includes discussion questions for participants and leader's version.
- Tools and resources to facilitate placement, understand symptoms and plan effective care. Order your packet online via <u>www.theaftd.org</u>

On-going Resources

- FREE Quarterly e-newsletter with case-based studies and interventions
- What to Do About....one page of succinct, hands-on interventions for common care management challenges
- The Partners in FTD Care Yahoo Group is a closed group, moderated by AFTD's experts to promote effective management strategies among professionals committed to quality care.

Recent case study topics include:

- In FTD, Roaming is Not Wandering
- FTD Symptoms or Pain How Can You Tell?
- When the Meaning is Lost Semantic Variant PPA
- It's Complicated! Incontinence Management in FTD

Register at www.theaftd.org or email: PartnersinFTDcare@theaftd.org



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

www.theaftd.org 267.514.7221 / 866.507.7222 ©2014 AFTD

THE TITLE TEAM

For families and friends of someone with FTD, raising awareness and funds for the disease may seem like a lonely task, since many people have never heard of FTD. In an effort to create a sense of community among grassroots fundraisers across the United States, AFTD has formed **The AFTD-Team**.

The AFTD-Team is comprised of every grassroots fundraiser, organizer and participant who steps up to raise awareness and funds for AFTD. Fundraisers may be spread from Connecticut to California, but they are all driven by a common goal of funding research, care, treatment and ultimately a cure. In addition, The AFTD-Team stands behind this declaration: Yeah...I'm here to Fight This Disease.

To make fundraising efforts a bit easier, AFTD has designed The AFTD-Team fundraising toolkit. It is 12 pages full of fundraising ideas; planning suggestions; a sample letter, thank you and press release; tips on handling expenses and donation information. Fundraisers can download The AFTD-Team on our website.

One of the exciting additions to AFTD's fundraising tools is called Givezooks!, an online peer-to-peer fundraising platform. Grassroots fundraisers can now create their own fundraising webpage, email their family and friends from the webpage, and collect donations online for their event. It's an easy way to raise money for AFTD. Creating a webpage takes about 20-30 minutes and is relatively intuitive through

Givezooks! Since October 2011, we've had more than 100 people take advantage of this software to raise more than \$268,000 for AFTD!

For those who don't have the time to organize and host their own fundraiser, AFTD recommends forming a team to participate in an existing walk or run. This means that another organization hosts the



event, but allows individuals to raise money for the charity of their choice. Go to www.runningintheusa.com to find local events that you can participate in to raise money for AFTD.

Each person who raises \$250 or more for AFTD through a fundraiser will receive a t-shirt with "The AFTD-Team" logo and tagline on the back. The shirts are 100% microfiber and wick away moisture. Fundraisers will be able to find the rest of their team in these bright red shirts...The AFTD-Team will certainly be noticed!

If you'd like to raise money to Fight This Disease, please contact Angie Maher at amaher@theaftd.org or 267.514.7221 x2530.

IT'S TIME TO TAKE ACTION AND VOLUNTEER!

Has frontotemporal degeneration (FTD) affected your life?

Do you want to help make a difference for families facing FTD now and in the future?



You can get involved today by joining a national network of volunteers making a positive impact in the world of FTD. The Association for Frontotemporal Degeneration (AFTD) needs the time and talents of volunteers everywhere to help bring awareness of FTD to the forefront.

Opportunities vary from leadership roles and residential facility outreach to hosting fundraisers. We will explore projects together that best suit your skills and preferences.

You will be provided with guidance and support to ensure that you have a satisfying and rewarding experience that will meet your individual goals.



Katie Brandt, New England Regional Coordinator Volunteer

Are you ready to take action?

TO LEARN MORE:

http://www.theaftd.org/about/volunteer

Contact Kerri Barthel Volunteer Manager 267-514-7221 / <u>kbarthel@theaftd.org</u> AstraZeneca is proud to support The Association for Frontotemporal Degeneration

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Welcome to the Association for Frontotemporal Degeneration 2014 Education Conference & Annual Meeting

ENVIVO PHARMACEUTICALS EnVivo Pharmaceuticals is a proud sponsor of this AFTD Educational Event

FRIDAY, MARCH 14, 2014

For more information about EnVivo, visit www.EnVivoPharma.com

<u>Notes</u>

<u>Notes</u>



Do You Like to Eat? Wanna Raise Some Awareness of FTD?

We've Got Just the (Meal) Ticket!

- *What:* AFTD's 2nd Annual "Food for Thought" Campaign: Make a meal and invite family/friends, host a bake/cider sale or engage a local restaurant to give back a portion of a night's sales to AFTD.
- *When:* Any day from October 5 October 12, 2014: We're concentrating our campaign around one week in an effort to garner national press surrounding FTD. The more Food for Thought events we have across the U.S. the better!
- *How:* Anything that involves food and a little FTD education is just the ticket. Volunteers are ready to guide you through the process. Put your city and state on the map as we reach for awareness across the nation!

Sign up to host an event today at the Food for Thought Table !

A volunteer liaison will contact you later this spring to get you started.

The Quest Continues

Building on a century of pioneering Tau Research

1907: Dr. Alois Alzheimer presents discovery of neurofibrillary tangles in a patient.

1968: Sir Martin Roth correlates the formation of tangles with Alzheimer's dementia.

1988:

Prof. Claude Wischik

and colleagues discover that the tangles are composed of tau protein and strive to develop a treatment to 'Strangle the Tangle.'

NOW:

TauRx initiates global Phase 3 clinical trials in Alzheimer's and FTD.

TauRx Therapeutics Therapies and Diagnostics for Neurodegenerative Disease

TauRx: Dedicated to halting the progression of Alzheimer's and Frontotemporal Dementia.

Clinical research is an important step in the development of new medicines for unmet clinical needs. In frontotemporal dementia (FTD), TauRx is currently conducting a Phase 3 clinical study to evaluate the safety and efficacy of its proprietary Tau Aggregation Inhibitor, LMTX[™], in patients with behavioral variant FTD (bvFTD).

This study is currently recruiting and patients and caregivers are invited to learn more by visiting:

www.FTDSTUDY.net

