

A Vision for Hope:

**The Early History of The Association for
Frontotemporal Degeneration (AFTD)**



A Vision for Hope

Prologue

1978

It's the late 1970s, and Helen-Ann Comstock has begun to notice concerning changes in her husband, Craig. It's 1978 – Craig is 44 – and Helen-Ann and her husband make an appointment with a neurologist near their home on the Monterey Peninsula, California. The neurologist suspects a brain tumor or a form of dementia, such as Alzheimer's disease.

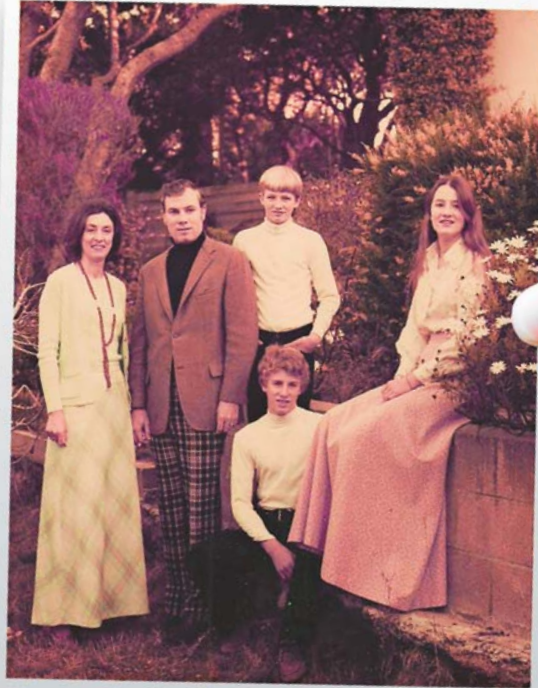
"Frankly, before my husband got sick, I had never even heard of Alzheimer's," says Helen-Ann. "It just wasn't a word that people knew or understood." The Alzheimer's Association wouldn't be founded until 1980.

Helen-Ann struggles to find information and resources. Her area's main library contains no books about Alzheimer's, and the most she can locate are two sentences in the Encyclopedia Britannica.

Although Craig is unconcerned, Helen-Ann wants a second opinion. Craig eventually receives a diagnosis of Alzheimer's from a neurologist at a major university hospital. Helen-Ann is told that there is no cure, no medicine that can be prescribed and nothing that can be done. Craig's neurologist only advises Helen-Ann to take him home and "accept a change in lifestyle."

The news is jarring, but another doctor on the neurologist's team also mentions the possibility of Pick's disease. He knows that Craig, a math professor with a PhD from Harvard University, is due to spend a sabbatical at an institute in Switzerland, and he recommends a doctor there who specializes in the condition.

Despite Craig's condition, arrangements have already been made for his Swiss sabbatical, and the entire Comstock family is looking forward to it. Helen-Ann



contacts the institute in Switzerland where Craig has been invited to spend his sabbatical and informs them of these developments. The institute remains willing to give Craig's sabbatical a try. "I don't think they understood much more about this disease than I did," says Helen-Ann. But in the moment, she's relieved and thankful for their support.

Within a few weeks of the family's arrival in Switzerland, it becomes apparent that Craig cannot keep up with his work. Helen-Ann contacts the Swiss doctor that their California neurologist had recommended, and he agrees to examine Craig. After interviewing and testing him every morning for five consecutive days, the doctor informs Helen-Ann that he believed Craig had Pick's disease – or what would today more commonly be referred to as FTD.

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What is FTD?

Frontotemporal degeneration (FTD) is the most common dementia for people under 60. FTD results in progressive damage to the temporal and/or frontal lobes of the brain. It causes a group of brain disorders that share many clinical features. It is also referred to as frontotemporal dementia, frontotemporal lobar degeneration (FTLD), and Pick's disease.

FTD differs from Alzheimer's disease in three important ways:

- It is relatively rare (approximately 60,000 people in the US, vs. more than 5 million).
- It brings a gradual, progressive decline in behavior and/or language, with memory usually relatively preserved.
- FTD occurs earlier in life, and is the most common dementia for people under 60. Onset has been seen as early as 21 years and as late as 80 years. Roughly 60% of cases occur in people aged 45-64 years (Knopman, 2011). FTD can affect work and family in profound and devastating ways.

While the specific symptoms and the specific progression vary for each individual, FTD is marked by an inevitable deterioration in functioning. The length of progression varies from 2 years to more than 20 years, with a mean course of 7-13 years from the onset of symptoms (Onyike and Diehl-Schmid, 2013). FTD predisposes individuals affected to serious complications such as pneumonia, infection, or injury from a fall. Pneumonia is the most common cause of death.

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1978–1985

Finding Help

After the family's return to the US, Craig retired from his teaching position. The Comstock family's income declined significantly, down to one-third of what it had been previously. The couple had two children in college and one in high school. Craig now required full-time supervision.

Helen-Ann explored care options, and read about the author Roald Dahl's care for his wife, Patricia Neal, after she had suffered a major stroke. "Though I knew that the situations were different, I thought I could do something similar for my husband," she remembers.

Helen-Ann recruited 25 friends, along with a speech therapist, to help with Craig's care. Each friend spent an hour each week completing brain-stimulating tasks with Craig. A host of activities, from running errands and solving math puzzles to regular bike rides, helped keep Craig mentally and physically active.

Unfortunately, his attention span dramatically decreased over six months. Craig could still complete simple tasks, and some friends still took him for

walks or on errands. Surprisingly, he could still play a somewhat complicated math game with one of his former university colleagues. "But we had to abandon most of my ideas to help him, because it was getting to be just too hard for him and for the volunteers," said Helen-Ann.

The family needed a change. Although friends in California had been marvelously helpful and supportive, Helen-Ann decided to move Craig and their children to the Philadelphia area, where their extended families lived.

Craig's decline continued following their move to the East Coast, reaching a point where he could no longer speak, feed himself or control his bodily functions.

"It was sad to see someone so bright and able continue to decline," Helen-Ann recalls today. "There was nothing we could do to stop it."



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1985–1998



Lisa Radin

“My Lifeline”

Craig’s death at 50 didn’t deter Helen-Ann from fighting for greater awareness of FTD. She began working for the Alzheimer’s Association, becoming the Executive Director of the Southeastern Pennsylvania chapter (now known as the organization’s Delaware Valley Chapter).

With the support of Dr. Murray Grossman, a neurologist from the University of Pennsylvania, Helen-Ann started a support group for Pick’s disease. Dr. Grossman arranged a space for the group to meet at one of UPenn’s buildings in Radnor, PA.

Lisa Radin, who was to become a founding member of AFTD’s Board of Directors, fondly remembers:

“I met Helen-Ann when I was searching for a support group. The FTD support group she started was my lifeline to help me cope with the difficult journey I had as a caregiver for my husband, who was diagnosed with FTD at 55.”

Founding a support group built momentum for what would ultimately lead to the organization’s founding. In the late 1990s, the support group began discussing the idea of holding a conference for Pick’s disease. Members Constance “Fytie” Drayton and Joyce Shenian helped Helen-Ann with planning; Lisa Radin served as coordinator.

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1999

First U.S. Conference

The first Pick's Disease Conference in the United States was held in May 1999 in Philadelphia, made possible by support from the National Institutes of Health (NIH), corporate donors, the Southeastern Pennsylvania Chapter of the Alzheimer's Association and contributions from a number of families.

Martin Rossor, MA, MD, FRCP, a British neurologist from the Institute of Neurology, London, was invited as keynote speaker. Under Dr. Rossor's direction, the Pick's Disease Support Group (PDSG) had been established in London, England. The PDSG newsletter was the only publication about Pick's disease available at that time, and it was widely read by members of Helen-Ann's support group.

The 1999 Pick's Disease Conference represented the first attempt to create national awareness for Pick's disease and FTD across the United States. Lisa Radin, the conference's coordinator, recalls that the event met with great success, and strong interest from both researchers and caregivers. It fostered growing collaboration between scientists worldwide, and drew new attention from the National Institutes of Health (NIH).



The Pick's Disease Support Group in the UK, today maintained by the organization Rare Dementia Support.

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2000–2001

An Organization Takes Shape

One year after the 1999 Pick's Disease Conference, a Consensus Criteria meeting for FTD was held at NIH in Washington, DC, co-sponsored by NIH and the Southeastern Pennsylvania chapter of the Alzheimer's Association. The objective: to agree on new diagnostic criteria for Pick's disease and FTD. During this time, Helen-Ann met with Dr. Jordan Grafman at NIH, who informed her that there had been some interest in creating more awareness for FTD through the establishment of a national organization.

He suggested that she found one.

In April 2001, following the Alzheimer's Association's Public Policy Conference in Washington, DC, Helen-Ann met with John Trojanowski, MD, PhD; Virginia M.-Y. Lee, PhD; and Murray Grossman, MD, EdD, all of the University of Pennsylvania. Momentum gathered for launching a national organization for Pick's Disease and FTD.

After retiring from the Alzheimer's Association, Helen-Ann again met with Dr. Grafman, to discuss NIH funding for FTD research, FTD patient advocacy and the future of FTD awareness. Dr. Grafman and Helen-Ann also discussed the creation of a national FTD organization.

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Founding Board member Kent Jamison and founding AFTD Medical Advisory Council member, Murray Grossman, M.D., Ed.D.

"I conveyed to Helen-Ann that with NIH, the squeaky wheel gets the grease," Dr. Grafman says. "I said that if you and other family members were energized by what befell your loved ones, then turn that tragedy into a positive, prosocial activity like organizing families so scientists and other healthcare professionals would begin to hear the call. Eventually, so would Congress, the NIH and other foundations."

During the next six months, Helen-Ann spent her free time gathering support for the formation of a new national organization, to be called the FTD Society. To form a Board of Directors, she contacted family members and FTD caregivers from across the country, many of whom she had met during the 1999 Pick's

Disease Conference. In addition, she gathered the support of leading FTD researchers and clinicians to form a Medical Advisory Council.

There was legal work to be done. Helen-Ann filed corporate papers for the new organization, then hired an attorney to aid in crafting bylaws and filing applications for 501(c)(3) nonprofit status.

"Doing the legal groundwork to solidify the FTD Society's reputation was a major asset to the fledgling organization," says founding Board member Kent Jamison. "One of the things we did right is that we did things right. Getting 501(c)(3)-certified, getting bylaws in place, doing the budget carefully... folks felt justified making significant contributions early on."

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2002–2003

Donations Honoring Those Lost to FTD

The organization created an initial mission statement. Helen-Ann opened a bank account for the organization and donated \$1,000 of her own personal funds. As she planned the first meeting of the organization's Board of Directors, the organization received its first memorial contributions – in memory of Hugh M. Parrish, husband of founding Board member Tess Parrish, who died in December 2002. Today, thousands of AFTD donors still drive this same vision for hope.

The organization held its first official Board meeting January 16–17, 2003 in Philadelphia, bringing together current and former care partners, and one neurologist. All were passionate about the need for FTD to have its own space, voice and resources to help those affected.

The Board further approved changing the organization's name to The Association for Frontotemporal Dementias, and approved bylaws. All Board members contributed financially to establish initial funding.

A logo and brochure were discussed. Kent Jamison envisioned a gate on the cover of the brochure, representing AFTD's gateway to help and a cure.

The AFTD Medical Advisory Council (MAC) launched with Dr. Murray Grossman serving as Chair. An outstanding group of leading medical clinicians and researchers became part of the original MAC, all of whom had experience working with individuals affected by FTD or with FTD research.

Council members included Tiffany Chow, MD; Carol Lippa, MD; M. Marsel Mesulam, MD; Thomas D. Bird, MD; Bernardino Ghetti, MD; Michael Hutton, PhD; Jordan Grafman, PhD; Virginia M.-Y. Lee, PhD; Irene Litvan, MD; Bruce L. Miller, MD; John C. Morris, MD; Linda E. Nee, MSW and John Q. Trojanowski, MD, PhD.



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AFTD's Founding Board:

AFTD's founding Board members at their first meeting in January, 2003. From left: Fytie Drayton, Joseph Becker, Joyce Shenian, Jordan Grafman (advisor), Tess Parrish, Helen-Ann Comstock, Lisa Radin, Kent Jamison. Founding Board members not pictured: Lawrence Shor, Robert Kemp, Robert Potamkin.

2002–2003

Addressing Huge Unmet Needs

Fytie Drayon, AFTD's first Board Treasurer, and Joyce Shenian, AFTD's first Board Secretary, each played vital roles. They collected mail from the post office, deposited checks, responded to memorial donations and correspondence, and produced financial reports. Tess worked on the newsletter and secured donations.

"I'm proud to have been one of the original Board members," says Joyce Shenian, whose husband, Popkin, formerly the first Director of Research and Development for the Plastic Division of General Electric, had been diagnosed with FTD after years of misdiagnosis.

Joyce assisted in developing AFTD's Governance Committee. "I was also the event planner for several years for the conferences and Board meetings on a national level," Joyce adds. This vital work reflected volunteer travel to scout conference locations and logistics – all at Joyce's own expense and on her own time as a volunteer. Today, hundreds of volunteers are the force bringing AFTD's impact – and the vital resources and connection we can offer – to local communities.



Joyce Shenian



Fytie Drayon

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*Founding members of AFTD's Medical Advisory Council,
(left) Virginia M.-Y. Lee, Ph.D.,
and (right) John Q. Trojanowski, M.D., Ph.D.*

"Getting involved with founding AFTD was so important because it addressed huge unmet needs – the most important being patient care, education and research that puts us on a solid course for discovering disease modifying therapies for FTD," remarked Dr. John Q. Trojanowski, a founding MAC member.

"I was impressed by [AFTD's] fortitude and commitment to helping find better ways to evaluate, manage, symptomatically treat and eventually find a way to prevent FTD," says MAC member Dr. Jordan Grafman.

Dr. Murray Grossman, the first MAC chair, saw growing recognition of FTD within the medical community. "People began to see the importance of FTD and, further, the importance of specializing in this area," he says.

In April 2003, AFTD was recognized internationally when founder Helen-Ann Comstock was invited to speak at the 4th International FTD Conference in Lund, Sweden. The organization's participation announced AFTD's presence to international researchers, and Helen-Ann was able to distribute newly printed AFTD brochures to conference attendees.

Kent Jamison created the official AFTD website in June 2003. "I was in a good position to map out what the website should look like," Kent says. "The big challenge was creating the content. Having a couple pages for each type of FTD, where they all had to be technically correct... was one component." The website launched on June 30 of that year.

2003–2004

National Recognition

AFTD gained important recognition on the national federal level in July 2003. Helen-Ann's son, Earl W. Comstock, who was then Legislative Director for Senator Ted Stevens (and later an AFTD Board member), worked with staff from Senator Arlen Specter's office to include language in the Senate Report to accompany the FY2005 Labor HHS Appropriations bill.

These lines directed the NIH to: continue and expand its research on Pick's disease and other frontotemporal dementias; to include consultations with researchers and clinicians in the field, as well as patient advocates; and to report back findings on their progress to the House and Senate.

Due to financial restraints, the workshop was not held until February 2007. However, the Senate mandate still gave much-needed recognition to FTD research in its early years. It also laid the groundwork for important relationships with the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute for Aging (NIA), and the Alzheimer's Drug Discovery Foundation (ADDF).

AFTD Board member Lisa Radin and her son Gary Radin edited and published *What If It's Not Alzheimer's?: A Caregiver's Guide to Dementia*. Members of AFTD's Board of Directors and Medical Advisory Council contributed chapters. The first book written specifically for FTD caregivers, today the book is a popular resource, in its third edition.

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Tess Parrish oversaw the publication of the first AFTD Newsletter in February 2004. Susan L-J Dickinson, MS, CGC, at that time a freelance writer, was hired to work with Tess on this effort. She also helped Kent Jamison to create handouts about each form of FTD, as well as genetic information.

Interest in FTD grew following the 4th International FTD Conference in Lund, Sweden. Since the next International Conference for FTD would not be held until 2006, Helen-Ann and MAC members Virginia Lee, John Q. Trojanowski and Murray Grossman decided to organize a satellite conference for FTD. The conference was held in conjunction with the 9th International Conference for Alzheimer's Disease in Philadelphia. The agenda included scientific sessions for both caregivers and scientists, following the example set at the 1999 Pick's Disease Conference.

Kent Jamison adds: "It was very uncommon for a scholarly conference to include caregivers, but Helen-Ann and I both felt strongly about including scientists

and caregivers together." For many of the researchers, it marked a chance to meet people affected by this devastating disease for the first time.

Joyce Shenian organized the dinner for caregivers, Board members, conference organizers and MAC members, as well as a reception for speakers and Board members.

For the FTD satellite meeting, AFTD also awarded its first travel grants, providing modest financial support to enable six caregivers from the United States and Canada to be part of the event in a template of what would become an impactful Comstock Grant program.

Medical Advisory Council member and Organizing Committee member John Q. Trojanowski notes: "We had anxieties about how well we would reach out to caregivers, but from what we have heard, this meeting was a success for them too. We may have even created a really exciting and user-friendly format for future meetings on other neurodegenerative diseases."



AFTD founding Board members Joyce Shenian, Dr. Jordan Grafman and Helen-Ann Comstock.

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2005

Growth and Change

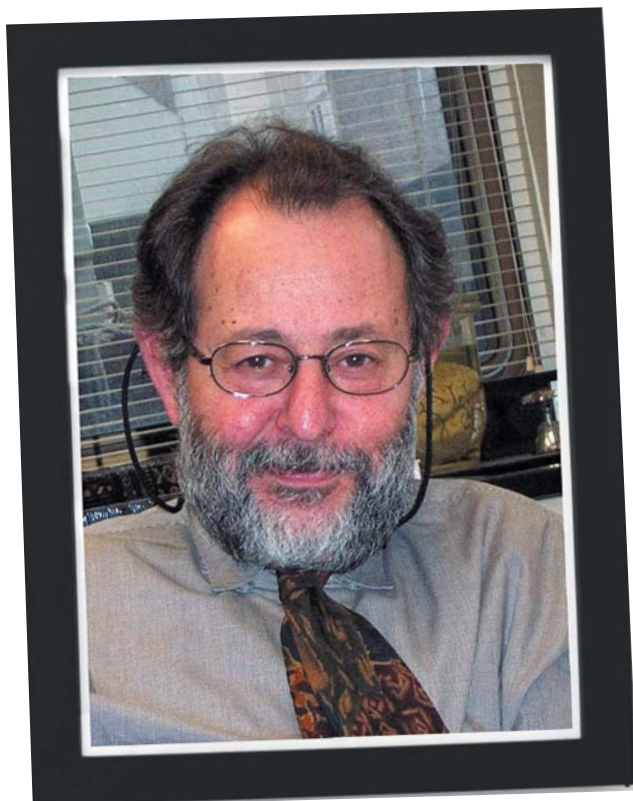
In February 2005, AFTD began working out of 100 North 17th Street in Philadelphia, using space generously donated by CARIE (The Center for Advocacy for the Rights and Interests of the Elderly). AFTD's first employee, Martha B. "Marty" Meyers, worked part-time as an office manager. During her tenure, Marty maintained responsibility for any and all mailings and phone correspondence, and worked closely with AFTD volunteers.

AFTD awarded its first research grant, in the amount of \$35,000, to Eileen Bigio, MD, in July 2005. A professor at Northwestern University Feinberg School of Medicine in Chicago, Dr. Bigio was chosen through a MAC subcommittee chaired by Dr. Virginia Lee.

"AFTD has been critical not only as an advocacy organization, but as a catalyst for research funding targeting FTD," said founding MAC member Dr. Marsel Mesulam, MD. "We were honored for a Northwestern University Feinberg School of Medicine researcher to receive this award, and grateful for AFTD's partnership in the work to address FTD."

AFTD established its toll-free HelpLine in September 2005, providing information and support to caregivers. Helen-Ann Comstock and Kent Jamison initially coordinated this effort, with help from MAC members.

Due to the efforts of new Board member Colleen Quinn, a telephone support group was started, with Colleen and Jennifer Farmer, a genetic counselor from the University of Pennsylvania, moderating.



*AFTD MAC member
Dr. Marsel Mesulam, MD*

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2006

Support and Connection

Catherine Pace-Savitsky, MA, joined the staff as AFTD's first Executive Director in February 2006. Catherine, who had previously worked as a clinical research associate and project manager for the Memory and Aging Center at the University of California, San Francisco, worked part-time overseeing the day-to-day activities of the growing organization, as well as its HelpLine.

There were now 14 FTD-specific caregiver support groups across the United States and Canada.

By August 2006, AFTD was distributing newsletters to nearly 1,000 caregivers, family members and professionals. AFTD literature was available in 46 states in the United States and on six continents. An average of 25 calls per month were coming in to AFTD's toll-free FTD HelpLine, and an average of more than 100 emails per month with informational inquiries reached AFTD's main email address.

Nearly three years after the establishment of AFTD, the organization was a major sponsor of the 5th International FTD Conference, held September 6-8, 2006 in San Francisco.

For the first time, the event included a day of programming for caregivers, with scientists brought in to present to them. MAC Member Dr. Bruce Miller of UCSF arranged an exhibit of art from persons living with FTD. "Bringing together the researchers seeking to address FTD with the families experiencing it had a powerful effect. For families, we were able to bring more information than had previously been available... For the scientists, as our understanding of FTD grew, it became anchored all the more powerfully in the perspectives of people living with FTD and their families. Deepening this dialogue can hasten the development of the first treatments for FTD," he says.

In addition to providing sponsorship funding for the Conference, AFTD hosted two dinners – one for caregivers and one for speakers. AFTD also funded several domestic and foreign caregiver travel grants. Helen-Ann received an award "in honor of her pioneering contributions to FTD awareness."

AFTD was admitted to the National Organization for Rare Disorders (NORD) that same month. AFTD was featured both on NORD's letterhead and website, and received informational updates and nonprofit management guidance.



*AFTD MAC member
Dr. Bruce Miller*

2007–2008

Increasing Awareness

The workshop mandated by language in the FY2005 Labor HHS Appropriations Bill, which was a direct result of advocacy by AFTD, finally came to fruition in January 2007.

The FTD Workshop was held at the Four Seasons Hotel in Miami, Florida, and co-sponsored by NINDS. The workshop had two key goals: reviewing and assessing the current state of FTD knowledge, and creating a prioritized list of objectives to move the field forward toward the development of new treatment options.

While AFTD and NINDS were the official sponsors of the workshop, the meeting would not have been possible without AFTD Board member Phil Lovett, who generously provided rooms and meals for all participants.

“The workshop was very successful and was one of the important first steps in establishing both AFTD and FTD as important causes,” remembers Phil.

A total of 33 leaders in FTD research, chosen by an Organizing Committee formed specifically for the workshop, participated. A special dinner for workshop participants was hosted by Board member Robert Potamkin at his Fisher Island home.

The direct outcome of the workshop was a report summarizing the findings on the current state and future of FTD research. Upon the workshop’s conclusion, Phil Lovett shared his thoughts: “Participants hope that this report will accelerate us along the path to new treatment strategies for FTD.”

The workshop also started an important partnership between AFTD and the Alzheimer’s Drug Discovery Foundation (ADDF), when Howard Fillit, MD, the founding Executive Director of ADDF, met with Helen-Ann and Phil Lovett. Dr. Fillit proposed that AFTD and ADDF team up to raise funding for FTD research. For every dollar raised by AFTD targeting Drug Discovery, ADDF would provide a two dollar match.

Within three years, AFTD had raised \$300,000, matched by an additional \$600,000 from ADDF. This money was used to seed the first grants for FTD Drug Discovery. “The partnership between AFTD and ADDF continues

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*Walter J. Koroshetz
MD, Deputy Director,
NINDS, with AFTD
Board members
Robert Potamkin
and Philip Lovett.*

to this day and has been extremely important to AFTD's past and recent successes," says Phil.

After beginning work with AFTD as a freelancer contributing to its first newsletter, Susan L-J Dickinson, MS, became AFTD's Executive Director in February 2008. Today, she is the organization's first Chief Executive Officer.

"What attracted me to work with Helen-Ann and the founding board was their steadfast personal commitment," says Susan. "Each member had faced a very personal, deep and traumatic loss. Yet here they were, rolling up their sleeves, answering HelpLine calls, donating from their savings, and creating an organization. All because they had a vision for hope."

AFTD cosponsored several caregiver conferences, including one cosponsored with the ALS Association in May 2008. This conference was held after the discovery that the protein TDP-43 was an important link between FTD and ALS.

"Success in finding therapies for rare FTD disorders will have a significant impact on the more common Alzheimer's disease," commented MAC member Dr. Virginia M.-Y. Lee. "We believe that combined therapies

targeting TDP-43 will be needed not only for FTD, but for Alzheimer's as well."

In June 2008, AFTD cosponsored another caregiver conference with the University of Pennsylvania, which had more than 230 caregiver attendees from across the nation. This conference was chaired by Dr. Murray Grossman, who was honored for his many years of dedicated leadership and service to AFTD.

AFTD held its first public annual meeting in Baltimore in June 2008, joined by caregivers, donors, and family members that represented a growing national audience. In September 2008, AFTD helped to sponsor the 6th International FTD Conference. Held in Rotterdam, the event drew together more than 350 clinicians and researchers, who shared research developments and future plans for FTD treatment and advocacy.

AFTD co-organized the conference's Caregiver Day, attended by more than 200 caregivers from continental Europe, the United Kingdom and the United States. AFTD also sponsored a dinner for caregivers, researchers and clinicians.

A Vision for Hope

October 27, 2008

Conclusion: Advancing a Vision

AFTD reached one of its most important milestones yet on October 27, 2008 – a day that saw FTD included in the Compassionate Allowances Initiative, at a time before Alzheimer's was. People with FTD became eligible to receive expedited review for Social Security claims. Individuals who previously waited years for disability approval might now see their applications reviewed in as little as one week.

A letter written on behalf of AFTD by Board member Kent Jamison had explained the concerns of persons with FTD when seeking disability benefits. The letter was included, along with input from FTD caregivers, in the testimony presented to the Social Security Administration by government officials. It was the driving force behind FTD's inclusion in the list of diseases eligible for a Compassionate Allowance.

Helen-Ann stepped down as Chair of AFTD's Board of Directors in May 2010. She remains on the organization's Board today. Beth Walter, who lost her husband to FTD in 2006, succeeded her as Chair.

"My family and I wanted to get involved since we had five family members affected," says Beth. "We needed answers. We didn't find AFTD until 2007, and I joined the board officially in 2008."

She continues: "It was important to me that during my tenure on the Board, AFTD make strides towards a more formal business structure, without losing the personal and heartfelt goals of AFTD's founder, founding Board, and all of us who dedicate our time and resources to this mission."

With AFTD's many early achievements, including the important Senate mandate for Pick's disease and other forms of FTD, as well as their landmark inclusion in the Compassionate Allowances program, attention to FTD was growing. Work by volunteers, donors and health professionals had established the organization as a crucial force for championing awareness and research. AFTD celebrated its 15th anniversary in November 2017 – knowing that while we spent those years making critical gains to awareness, much remains to be done if we are to achieve a world with compassionate care, effective support, and a future free of FTD.

Thank you for reading our history. We would like to thank every Board member, staff member and volunteer who has contributed to the growth of AFTD. Each of you is playing a role in changing the story of FTD – in seeing AFTD's mission advanced, and its vision achieved.



A Vision for Hope

AFTD Staff, Advisors and Volunteers, In Their Own Words



"The establishment of AFTD and the ramping up of its activities had a profound effect on awareness of FTD for not only Congress but physicians and scientists – especially via national and international

scientific meetings. But just as importantly, family members taking care of people with FTD now had a resource to go to for all sorts of helpful information, ways to get energized to draw attention to the disorder, and sometimes just a sympathetic ear. I know many family members I talked to were grateful that AFTD came into being."

Dr. Jordan Grafman,
founding MAC member



"There is so much more information available [on FTD] for both caregivers and people with FTD now than there was 15 years ago, and AFTD has played a crucial role."

Dr. Murray Grossman,
founding MAC Chair



"Caring for my husband with FTD inspired me to devote my time, effort and financial support as a founding Board member. Later my son, Popkin, served on the Board and was instrumental in obtaining significant funds

from NIH for FTD research. Without so many caring people, we would not be where we are today with this organization."

Joyce Shenian,
founding Board member



"AFTD will continue to increase the outreach, the science and the care to our population, expanding on each of those efforts. As a result, FTD will become better understood and receive more focused attention about a need for a cure."

Beth Walter, former AFTD
Board Chair and current Board member



"Through the strength of our volunteers and donors, I see us continuing to grow and build confidence and momentum across our community. The next five years will bring significant change to this field, and I'm eager

for us to accomplish key gains with – and on behalf of – people living with FTD, their care partners, and their families."

Susan L-J Dickinson, AFTD CEO



"Staffing the HelpLine was one of the most gratifying and most challenging aspects of my job. The work informed our decision to build a more robust regional volunteer support network, as well as more specialized telephone support groups."

Catherine Pace-Savitsky, MA,
AFTD's first Executive Director



"I think we have been very fortunate, but we've also had a very hard-working Board and a marvelous staff. I am proud of what we have accomplished and look forward to building on that. I eventually see a world where

FTD is prevented and no longer exists to bring such devastation."

Helen-Ann Comstock, AFTD founder
and founding Board Chair





The Association for
Frontotemporal Degeneration
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