OUR HISTORY 2002-2012

The Association for Frontotemporal Degeneration (AFTD) was founded (as the Association for Frontotemporal Dementias) by Helen–Ann Comstock in 2002. The organization is the product of her experience as an FTD caregiver and collaboration with scientists, physicians and other caregivers who echoed the need for increased attention to these devastating diseases. A timeline of milestones in the organization’s development follows:

**November 2002** – Founding of AFTD. Convinced of the need for an organization dedicated specifically to improving the lives of families coping with FTD and advancing research into treatment and a cure, and encouraged by caregivers and researchers alike, Mrs. Comstock founded AFTD. She organized a Board of Directors comprised of current and former caregivers and one neurologist to guide the new organization. Founding board members were: Constance Drayton, Tess Parrish, Lisa Radin, Joyce Shenian, Kent Jamison, Helen-Ann Comstock, Robert Potamkin, Joseph Becker, Robert Kemp, and Lawrence Shor.

**January 2003** – First meeting of the AFTD Board of Directors in Philadelphia, PA was held.

**March 2003** – The Medical Advisory Council, comprised of leading researchers, clinicians and health care professionals working in FTD, was established as a critical partner in the organization’s mission.

**April 2003** – Helen-Ann Comstock was invited to speak at the 4th International Conference on FTD in Lund, Sweden, about the founding of AFTD and its mission. This announced the organization to international researchers.

**June 2003** – Board member Kent Jamison designed and launched AFTD’s website to increase education and outreach to caregivers. The organization’s first newsletter followed in early 2004.

**July 2003** – Advocacy by Helen-Ann Comstock and her son Earl resulted in a mandate for FTD research to be included in a Senate appropriations bill.

**July 2004** – FTD Symposium for researchers and caregivers was held immediately prior to the 9th International Conference on Alzheimer’s Disease in Philadelphia, PA. It was arranged by Drs. Murray Grossman, Virginia M.-Y. Lee, Bruce Miller, John Trojanowski, and John van Swieten, with caregiver activities coordinated and supported by AFTD. AFTD awarded the first travel grants to six caregivers from the US and Canada, hosted a caregiver dinner, and a
Our History  2002-2012 (Cont.)

reception for board members, conference speakers, and AFTD Medical Advisory Council members.

**February 2005** – The AFTD office was established in Philadelphia with Martha B. Meyers hired as its first employee. One year later, Catherine Pace-Savitsky was hired as AFTD’s first Executive Director. Both worked on a part-time basis.

**July 2005** – AFTD’s first **research grant** was awarded in the amount of $35,000 to Eileen Bigio, MD, Northwestern University, Feinberg School of Medicine, Chicago, IL.

**September 2005** – The toll-free Helpline started to provide information and support to caregivers. Board members responded to Helpline messages. In November 2005 AFTD started a telephone support group and connected a network of 14 FTD caregiver support groups across the US and Canada.

**September 2006** – AFTD was a major sponsor of the 5th International Conference on FTD in San Francisco, CA.

**January 2007** – Together with National Institute of Neurological Disorders and Stroke (NINDS) and National Institute on Aging (NIA), AFTD sponsored a workshop in Miami, FL for leaders in the field to assess the state of FTD research and treatment.

**May 2007** – In the wake of researchers’ identification of TDP-43 as the common protein linking FTD and ALS, AFTD and the ALS Association co-sponsored a conference for caregivers in Philadelphia.

**July 2007** – AFTD formed a partnership with the Alzheimer’s Drug Discovery Foundation (ADDF) to **fund the first grants for FTD Drug Discovery**. AFTD embarked on a three-year campaign to raise $300,000, which was matched by $600,000 from ADDF. The initial partnership has been extended and continues to fund researchers working toward discovery of the first treatments for FTD.

**June 2008** – The first Annual AFTD Public Meeting was held in Baltimore, MD, and attended by nearly 100 caregivers, family members and friends. AFTD also published its first annual report.

**September 2008** – AFTD was a sponsor of the 6th International Conference on FTD in Rotterdam, The Netherlands. AFTD also co-organized a meeting with international caregiver organizations. AFTD hired its first Program Director.
October 2008 – FTD was included as one of just 50 rare diseases in the Social Security Administration’s new Compassionate Allowances program, under which patients with a diagnosis of behavioral FTD receive expedited review of their applications for Social Security benefits. Primary Progressive Aphasia was added in 2010.

January 2009 – AFTD awarded the first FTD Postdoctoral Fellowship. This two-year fellowship was funded by a generous gift from the Laden family.

March 2009 – AFTD created a pilot Caregiver Respite program to provide financial assistance grants for caregivers. The initial start-up donation of $10,000 was used within the first month. AFTD now awards $30,000 annually to encourage family caregivers to utilize respite services.

November 2009 – The AFTD Board of Directors adopted a four-year strategic plan, completing the first-ever long-term planning process for the organization. The Board re-committed to the full breadth of the organization’s mission, approved an official vision statement, and adopted six strategic priorities for growth.

May 2010 – Founder Helen-Ann Comstock retired as Board Chair, passing leadership of the organization to Beth Walter. The effective transition from founding board members to new leaders reflects the organization’s stability and vitality.

December 2010 – The AFTD Board of Directors unanimously voted to change the organization’s name to The Association for Frontotemporal Degeneration. The change was adopted after a two-year review and recognizes changing medical terminology and AFTD’s desire to serve patients and caregivers living with any of the subtypes of FTD.

February 2011 – AFTD released It Is What It Is, an 18 minute film that represents a major effort to promote awareness of FTD. The film is introduced by Beth Walter, AFTD board chair, and interweaves the stories of four families as they describe the impact FTD has had on their lives.

December 2011 – AFTD took ownership for the Frontotemporal Degeneration Treatment Study Group (FTSG), which is designed to accelerate the development of effective treatments for FTD and related disorders by promoting scientific interactions and collaborations between academia and industry.

October 2012 – AFTD celebrates its 10th anniversary with a fundraising event in Philadelphia. A commemorative video highlights the milestones and accomplishments of the last decade of dedication.