

50 Years of Research, Progress, Hope

Before the CF Foundation was founded in 1955, there were several important milestones that occurred in cystic fibrosis (CF). In 1938, Dorothy Andersen, M.D., the person commonly credited for “discovering” CF, first described the symptoms of the disease and gave it the name, “cystic fibrosis of the pancreas.” In 1953, CF pioneer Paul di Sant’Agnese, M.D. of Columbia University, developed the sweat test to diagnose CF. This test, which measures the chloride content in sweat, remains the gold standard for diagnosing CF and has made a tremendous difference in the lives of thousands of people by enabling proper diagnosis and follow-up care. With the establishment of the CF Foundation, progress in understanding and treating this disease began in earnest. Everyone involved with the CF Foundation—be they patients, family members, caregivers, volunteers, donors or staff—knows the urgency and need for medical milestones in CF. Through this timeline, we chronicle the history of many of those milestones. We also wish to recognize some of the many people and events that have fueled those medical advances and to acknowledge their impact in the fight against this disease.

- 1955** A group of volunteers, including parents of children with CF and physicians meet to form the CF Foundation, headquartered in Philadelphia; among the group is Milton Graub, M.D., a pediatrician and father of two children with CF, who later becomes the CF Foundation’s third president and who remains active in the CF Foundation today; life expectancy for people with CF is 5 years old.
- 1961** The CF Foundation establishes the first CF care centers; CF Foundation hosts first conference of CF care center directors.
- 1962** Additional CF centers established, bringing total to 30.
- 1965** CF Foundation begins clinical fellowship program; George Frankel, a CF Foundation founder, establishes Guidance, Action and Projection conferences, a fellowship program to bring basic scientists into the field of CF research
- 1966** CF Foundation establishes Patient Data Registry, which tracks the histories of patients treated at CF care centers.
- 1968** CF Foundation hosts first National/International Medical Conference.
- 1972** First national seminar on needs of young adults with CF held by CF Foundation.
- 1978** Headquarters moves to Washington, D.C. to be close to the federal government and the National Institutes of Health (NIH); first nationwide fund-raising event held, called *Bowl for Breath*, nearly doubling the fund-raising dollars for CF.
- 1980** Robert J. Beall, Ph.D. comes to the CF Foundation as medical director from NIH.
- 1981** Satellite CF care centers for adults were established for the first time; life expectancy reaches 20 years.
- 1982** The CF Foundation creates the Research Development Program (RDP) to encourage leading academic and scientific institutions to establish centers of excellence in CF research; Doris Tulcin, Chairman Emeritus of CF Foundation, launches a capital campaign—the first of its kind by a voluntary health agency—to raise \$15 million to support the creation of the RDP; Robert K. Dresing becomes volunteer president of the CF Foundation, later becoming the first president and CEO.
- 1983** Scientists show that cells lining the lungs fail to properly move chloride into the airways; the Orphan Drug Act is signed into law and provides companies with financial incentives for developing drugs for rare diseases like CF; Frank Deford, sportswriter and novelist, writes the book, *Alex: The Life of a Child* about his daughter who died from CF at the age of 8; Deford becomes Chairman of the CF Foundation’s Board of Trustees.
- 1984** American Airlines, Outstanding Corporate Partner of the CF Foundation, hosts the first *Celebrity Ski* event to benefit the CF Foundation.
- 1985** Life expectancy reaches 25 years.

- 1986** The movie, "*Alex: The Life of a Child*" appears on ABC putting CF in the national spotlight; CF Foundation tops \$20 million in fund-raising.
- 1988** CF Foundation creates CF Services, Inc., a national pharmacy that offers all people with CF access to CF medications and therapies.
- 1989** Francis Collins, M.D., Ph.D., John Riordian, M.D., and Lap-Chee Tsui, Ph.D. discover the CF gene with support from the CF Foundation's RDP; CF Foundation hosts first GREAT STRIDES walk-a-thon, now a \$20 million+ annual fund-raising event.
- 1990** CF researchers achieve test tube "proof of concept" for gene therapy.
- 1993** FDA approves Pulmozyme, the first biotech drug designed for CF, which breaks down thick CF mucus following studies in CF care center network; first gene therapy tested in person with CF—shows gene therapy corrects CF cells in nasal passages; CF Foundation and NIH establish nine gene therapy centers for CF studies; Beall becomes president and CEO of the CF Foundation; The Boomer Esiason Foundation redirects its mission to support the CF Foundation when Esiason's son, Gunnar, is diagnosed with CF.
- 1996** The Seattle *Breath of Life Gala*, which has raised more than \$24 million since its inception in 1984, becomes the CF Foundation's first "million dollar event," raising \$1,002,500 in one night; CF Foundation forms public policy alliance, a grassroots group of volunteers who inform policy decision makers.
- 1997** FDA approves TOBI, an inhaled antibiotic, after CF Foundation-supported studies showed safety and efficacy; CF Foundation establishes the Therapeutics Development Program (TDP) with seven centers in the Therapeutics Development Network (TDN); CF Foundation forms Adult Task Force to address specific issues facing adults with CF.
- 1999** Bill and Melinda Gates Foundation gives the CF Foundation a \$20 million grant for drug discovery; Cam C. Cooper is named Chairman of the CF Foundation's Board of Trustees.
- 2000** CF Foundation-supported researchers complete map of *Pseudomonas aeruginosa* genome; CF Foundation establishes CF National Bioinformatics Center to help spur discovery of new treatments; CF Foundation awards contract to Aurora Biosciences for up to \$46.9 million for CF drug discovery (the largest grant of its kind by a nonprofit organization); CF Foundation establishes Cystic Fibrosis Foundation Therapeutics, Inc. to govern CF Foundation's drug discovery and evaluation efforts.
- 2001** Tom Marsico, CEO of Marsico Capital Management, LLC, commits \$25 million over several years in support of the TDP; CF Foundation makes first multi-million award for drug development with Altus[®] Pharmaceuticals, Inc. to develop TheraClec[™] Total, a potentially more efficient pancreatic enzyme.
- 2002** Results of CF Foundation-supported clinical trial on azithromycin show that the drug is effective in improving lung function in people with CF; the TDN expands to 18 centers.
- 2003** Targeted Genetics, Inc., with CF Foundation support, begins a Phase II CF gene therapy trial that represents the largest and most advanced gene therapy trial for CF to date; CF Foundation tops \$150 million in fund-raising; CF Foundation launches Volunteer Leadership Initiative, to bring 2,003 new volunteers to the CF Foundation in 2003.
- 2004** Results from Inspire Pharmaceutical's CF Foundation-supported clinical trial of INS37217 to restore ion transport demonstrate both safety and improvement in lung function in people with CF; pipeline of CF therapeutics in development includes nearly two-dozen potential therapies; CF Foundation recommends nationwide newborn screening for CF at North American CF Conference, which now includes nearly 3,000 attendees; life expectancy increases to the mid- 30s.