
CFRI's Patrick Nash
Fellows Training Program
Aging in the New Era of Cystic Fibrosis
2nd Annual Symposium
October 3 - 5, 2025
Chicago, IL
CFRI Cystic Fibrosis Research Institute
RESEARCH · EDUCATION · ADVOCACY · SUPPORT

Welcome

Dear Friends,

It is our honor to welcome you to the Cystic Fibrosis Research Institute's Patrick Nash Fellows Training Program, *Aging in the New Era of Cystic Fibrosis*. Continued progress in cystic fibrosis (CF) therapeutics and care delivery has driven a rapid increase in life expectancy for those living with CF. The next frontier of extending and improving the lives of people with CF is to better understand and address the host of non-pulmonary CF-related comorbidities that present or progress in adulthood. Members of the second cohort of fellows represent 14 institutions from across the United States, and specialize in diverse subspecialty training programs.

This training program honors James Patrick Nash, or Patrick, who was born in 1967 and diagnosed with CF in 1972, concurrent with his sister Elizabeth. He passed away at the age of 55 after a short battle with pancreatic cancer.

Pat saw his life as one of great possibilities and passionately pursued the things he cared about. He earned his undergraduate degree from Boston College and his MBA from the University of North Carolina Chapel Hill; married the love of his life; had a decade-long career in corporate finance at Intel; and at age 36 welcomed beloved twin children. Pat retired in 2005 to invest more time in both his family and maintaining his health. He believed strongly in sharing his gifts with others and devoted significant time and energy as a youth basketball coach, school board member, CF clinical trial participant, and trusted confidant and advisor to his many friends. Patrick also believed strongly in the importance of exercise and spent countless hours swimming in the ocean, riding his Peloton, and running stairs to maintain his physical and mental health and to feed his competitive spirit.

Patrick's involvement in the CF community blossomed with the onset of COVID as he began to connect virtually with other CF-affected adults and recognized the breadth of challenges, outside of core CF disease, that his peers were facing. In 2021 he joined CFRI's CF Adult Advisory Committee and also began work to improve screening protocols for GI cancers in CF patients. This program is an important part of his legacy.

We thank you for your commitment to adult CF care. We look forward to a weekend of learning, engagement, discussion, new friendships, and supportive mentorship. Together, we will advance research, identify emerging needs, and develop improved clinical care strategies to address the concurrent impacts of cystic fibrosis and aging.

In partnership,
Members of the Steering Committee:
Steven Freedman, MD, PhD
Richard Moss, MD
Carolyn Nash
Christine Nash, MBA
Ahmet Uluer, DO, MPH
Siri Vaeth, MSW
James Yankaskas, MD

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CFRI's Patrick Nash CF Fellows Training Program "Aging in the New Era of CF," is made possible with support from the Nash Family as well as Vertex Pharmaceuticals.

VERTEX

Symposium Schedule

Friday, October 3

3:00 pm	**Welcome & Introduction to the Program** Siri Vaeth, MSW
3:30 pm	**Symposium Mission & Aims** Ahmet Uluer, DO, MPH
4:00 pm	**Introduction to Becoming Part of a CF Care Center** Whitney Brown, MD *Tresse (TJ) Chipres*
4:45 pm	**Socioeconomic Considerations for Adults Aging with CF** Michael Schechter, MD, MPH *Georgia Brown*
5:45 pm	**Break**
6:15 pm	**Dinner**
7:15 pm	**Keynote Address: Unrelenting Hope - Finding the Courage to Breathe Bravely** Ashley Ballou-Bonnema, MM

Saturday, October 4

7:45 am	**Breakfast**
8:30 am	**Aging in the Era of Highly Effective Modulators: A New Frontier in CF Care** Manu Jain, MD *Peter Gianopulos*
9:30 am	**Increased Risk of GI and Other Cancers in People with CF** Steven Freedman, MD, PhD *Ashley Ballou-Bonnema, MM*
10:30 am	**Break**
10:45 am	**Mental Health Considerations for Adults with CF** CJ Bathgate, PhD *Alex Gantt*
11:45 pm	**Lunch**
	NTM Infections in Cystic Fibrosis Elaine Cagnina, MD, PhD
12:45 pm	**Endocrine Complications in the Aging CF Population: CF-Related Diabetes** Melissa Putman, MD, MMSc *Steven Yankopoulos*

Saturday, October 4 (continued)

1:45 pm	**CF Airways Infection: That Was Then and This Is Now** **Antimicrobial Management in CF** Patrick Flume, MD *Brent Pace*
2:45 pm	**Break**
3:00 pm	**Endocrine Complications in the Aging CF Population: CF-Related Bone Disease** Melissa Putman, MD, MMSc *Joan Finnegan Brooks*
4:00 pm	**Cardiovascular Disease: Modulator and Non-Modulator Associated Hypertension, Obesity, CFRD** Ahmet Uluer, DO, MPH *Stephen McParland*
5:00 pm	**Optimizing One's CFRI Patrick Nash Fellows Experience:** **Panel of 2024 Patrick Nash Program Cohort Members** Ted Cybulski, MD, PhD Alex Despotes, MD Sandy Sufian, PhD, MPH
5:45 pm	**Break**
6:45 pm	**Offsite Dinner**

Sunday, October 5

7:45 am	**Breakfast**
8:30 am	**Sleep Disturbances in CF** Elizabeth Tullis, MD *Gordon Dart*
9:30 am	**Pharmaceutical & Pharmacological Implications in CF and Aging** Alex Philbrick, PharmD, BCPS *Colleen Lewis*
10:30 am	**Reproductive and Sexual Health** Jennifer Taylor-Cousar, MD, MSCS *Crystal Boeckel; Peter Sengelmann*
11:25 am	**Break, Hotel Checkout, Cohort Photo**
11:45 am	**The Path Forward** Ahmet Uluer, DO, MPH
12:30 pm	**Symposium Ends**

Faculty & Steering Committee

CJ Bathgate, PhD

Faculty

CJ Bathgate (she/her/hers) is an Associate Professor of Medicine and Clinical Health Psychologist in the Division of Neurology and Behavioral Health at National Jewish Health (NJH) in Denver, CO. Dr. Bathgate focuses on the mental health and emotional well-being of adults with cystic fibrosis (CF). Dr. Bathgate earned her BA in psychology from the University of Michigan, MA and EdM in counseling psychology from Columbia University, and MA and PhD in clinical health psychology from the University of Colorado. She completed her clinical internship at the University of Arizona and a postdoctoral fellowship in behavioral sleep medicine at National Jewish Health in 2016, where she has continued to lead CF-focused mental health initiatives for the past 9 years. Her clinical and research interests span mood, sleep, stress, neurocognition, health behaviors, and quality of life across the CF lifespan and in the context of CFTR-modulator use. She has been a Principal Investigator and/or Co-Investigator on numerous CF mental health studies, with recent studies including the development and testing of the Coping and Learning to Manage Stress with CF (CALM) telehealth program; Promoting Access to Create Hope and Healing (CF-PATCH): A study examining interpersonal violence in CF; the General Mental Health Screener in CF (GEMS-CF); and Restarting Triple Therapy with Robust Monitoring for Adverse Events (RETRIAL) study. Dr. Bathgate serves as vice chair of the CF Foundation-funded PRIME (Prioritizing Research in Mental Health) working group and will assume the role of Chair in 2026. She is in her fourth year on the North American Cystic Fibrosis Conference Program Planning Committee and collaborates internationally with the European Cystic Fibrosis Society's Mental Health Working Group, and nationally with the Success with Therapies Research Consortium and Mental Health Advisory Committee.

Whitney Brown, MD

Faculty

Dr. Whitney Brown serves as the Vice President of Clinical Affairs at the Cystic Fibrosis Foundation. She earned her undergraduate degree from the University of North Carolina Chapel Hill and completed her medical education at Emory University. Following her internal medicine residency at New York Presbyterian Hospital/Cornell, Dr. Brown returned to UNC-Chapel Hill for specialized training in pulmonary and critical care, where she developed a particular expertise in caring for adult patients with CF and lung transplantation. In 2010, Dr. Brown joined the Inova Advanced Lung Disease & Transplant Program in Falls Church, VA and was the founding Director of the Adult CF Program. In July 2021, she took on a new challenge at the CF Foundation, focusing on the evolving needs of the CF Care Center network and the growing population of individuals living longer, fuller lives with CF. Despite her administrative role, Dr. Brown remains actively engaged in patient care at Inova, a commitment that continually energizes and informs her work at the CF Foundation.

Elaine Cagnina, MD, PhD

Faculty

Elaine Cagnina, MD, PhD is an adult pulmonologist at Brigham and Women's and Boston Children's Hospitals where she is the associate medical director of the adult CF program. She was the associate director of the adult CF program at the University of Virginia before moving to Boston in 2018 and has been working in CF as a primary clinical focus since 2016. She has a special interest in complex lung infections in CF and other lung conditions which stems directly from her basic science research studying the host immune response to fungal pathogens. She has been highly invested in the

training of pulmonary fellows and medical residents throughout her career and is excited to help train the next generation of physicians and scientists to advance the care of people with CF.

Patrick Flume, MD

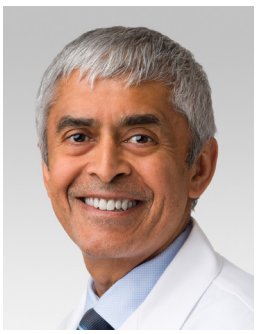
Faculty

Patrick Flume is a Distinguished Professor of Medicine and Pediatrics and Associate Vice President for Clinical Research at the Medical University of South Carolina. He serves as the Powers-Huggins Endowed Chair for Cystic Fibrosis (CF) and oversees a large CF center, as well as large clinical programs dedicated to patients with bronchiectasis and non-tuberculous mycobacterial (NTM) infections. He leads a busy clinical research program for CF, bronchiectasis, and NTM, and is co-principal investigator for the South Carolina Clinical & Translational Research Institute.

Steven Freedman, MD, PhD

Faculty & Steering Committee

Steven Freedman, MD, PhD, is Director of the Pancreas Center at Beth Israel Deaconess Medical Center, Chief of the Division of Translational Research, and Professor of Medicine at Harvard Medical School. He has played a leadership role in clinical/translational research at Harvard through his prior role as the Associate Dean for Clinical and Translational Research and Co-Director of the Harvard CTSA (Harvard Catalyst). He is Director of the Grant Review and Support Program, a unique longitudinal program that provides project management support and grant writing tools to enhance the transition from an NIH K to R01 grant for junior faculty across Harvard. Dr. Freedman's expertise is in exocrine pancreatic disease with a focus on pancreatitis, pancreatic cancer, pancreatic enzyme development and cystic fibrosis as well as diseases of premature infants with a translational research focus on fatty acid metabolism. He helped establish the CF Foundation-funded DIGEST program to train pediatric and adult gastroenterologists in the GI aspects of CF and plays a leadership role for the CF Foundation to design, develop and carry out GI related CF research.



Manu Jain, MD

Faculty

Dr. Jain is a Professor of Medicine and Pediatrics at Northwestern University's Feinberg School of Medicine. He graduated from Northwestern University with a Bachelor of Arts degree in Biochemistry and received his MD from The University of Chicago where he also completed his residency in Internal Medicine and fellowship in Pulmonary Critical Care. He joined the faculty at Northwestern in 1996 and has risen to the ranks as a full professor. He has received intramural funding from the NIH, Veteran's Administration and CF Foundation for his investigator-initiated research. He has also been the director of the adult CF program at Northwestern since 1998. He has published more than 100 peer-reviewed articles and has been on numerous national CF boards and committees. He served as the adult program representative on the CF Foundation's planning committee for the North American Cystic Fibrosis Conference for 10 years. In addition, he has been on the Therapeutics Development Network (TDN) steering committee and has been the past chairman of the TDN protocol review and co-chair of the Guidelines Steering Committee. He is presently co-chair of the Genetic Therapies Working Group for CFF. He is on the editorial board for the AJRCCM and has been a reviewer for JCI, CHEST, Thorax, EMBO molecular medicine, Journal of CF, Translational Research among other journals. He has also served as an ad-hoc reviewer for numerous NIH panels, CFF, VA administration and CF Canada.

Faculty & Steering Committee

Richard Moss, MD

Faculty & Steering Committee

Richard B. Moss, MD, Professor Emeritus of Pediatrics at Stanford University, is former chief of the pediatric pulmonary and allergy divisions, and former allergy-immunology and pulmonary fellowship training programs director at Lucile Packard Children's Hospital Stanford. He was educated and trained at Columbia (BA), SUNY Downstate (MD), Children's Memorial Hospital of Northwestern University (pediatric residency) and Stanford (allergy-immunology and pulmonology fellowships). He was Director of the Stanford Cystic Fibrosis Center from 1991 to 2009 and a principal investigator for the Cystic Fibrosis Foundation's Therapeutics Development Network, where he also served as inaugural Chair of the Protocol Review Committee. He is a member of Stanford's Child Health Research Institute and has served on Stanford's Pediatric Mentoring Program for trainees and junior faculty, the Executive Committee of Spectrum Child Health (Stanford's NIH-funded clinical research program) and the Stanford IRB. Dr. Moss has reviewed and consulted for the NIH, CFF, national and international foundations, and many peer-review bioscience journals and biopharmaceutical companies. He has published over 250 research papers and is a frequent speaker at national and international medical conferences. His research interests have included pathogenesis, outcome measures, and treatment of chronic airway diseases of childhood such as asthma, CF and chronic lung disease of infancy, with an emphasis on mechanisms of pulmonary immunity, inflammation and allergy. Recent work has focused on allergic fungal lung disease and clinical testing of novel CF tests and treatments. He joined CFRI's Board of Directors in 2015.

Carolyn Nash

Steering Committee

Carolyn Nash recently retired from her role as Chief Operating Officer and Senior Vice President of Red Hat, Inc., where she also served as Chief Financial Officer. A seasoned technology executive and board-level leader, Carolyn now serves as a strategic advisor in the technology industry, drawing on decades of experience to help high-growth companies scale operations, drive innovation, and navigate complex transformations.

Carolyn has been involved with the CF community for over 30 years, initially via marriage to the late Patrick Nash and later as the co-founder and Chief Financial Officer of the Elizabeth Nash Foundation, an organization dedicated to improving the lives of individuals affected by CF and established in honor of her late sister-in-law.

Christine Nash, MBA

Steering Committee

Christine is a strategic advisor and Board member in the biopharma industry focusing on helping companies bring new medications to market for the treatment of rare diseases. Her most recent full-time role was Chief Commercial Officer for Hyperion Therapeutics, a company focused on the treatment of urea cycle disorders. She earned a BA in Public Policy and an MBA, both from Stanford University.

Christine has worked in partnership with CFRI since 2003 when she, her parents, her sister-in-law Carolyn, and her late brother Patrick co-founded the Elizabeth Nash Foundation in honor of her CF-affected sister Liz who died at age 32. The foundation seeks to improve the lives of people affected by CF with a particular focus on education and CF research. In July 2025, Christine was the recipient of CFRI's Volunteer of the Year Award, due her outstanding contributions to CFRI and service to those living with cystic fibrosis.

Alexander Philbrick, PharmD, BCPS

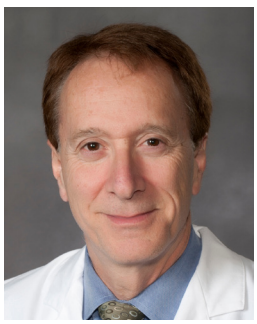
Faculty

Alex Philbrick is a clinical pharmacist with the Adult Cystic Fibrosis Center at Northwestern, he also works as a clinical pharmacist in the Northwestern Medicine Infectious Diseases Clinic. He completed his pre-pharmacy and Doctor of Pharmacy coursework at Purdue University in West Lafayette, graduating in 2002. After graduation, he completed a Pharmacy Practice Residency and a Specialty Residency in Infectious Diseases at the Hospital of the University of Pennsylvania. He has held various positions in a variety of practice settings (academic, inpatient, community, PBM) before taking a position at NM Specialty Pharmacy in April 2016; he transitioned to the ID clinic in March 2024. In November 2016, he received the Implementation of Outpatient Clinical Pharmacy Services Award from the Cystic Fibrosis Foundation, which allowed him to establish clinical pharmacy services in the Northwestern Adult CF clinic. He has served on the CFF Liver Disease Guidelines Committee, and currently serves on the CFF Guideline Steering Committee.

Melissa S. Putman, MD, MMSc

Faculty

Dr. Putman is an adult and pediatric endocrinologist at Massachusetts General Hospital (MGH), an Associate Professor of Medicine at Harvard Medical School, and the Director of the MGH Diabetes Research Center. She cares for adults with cystic fibrosis alongside their pulmonologists and other providers in the MGH Adult CF Program. With funding from the NIH and Cystic Fibrosis Foundation, she performs clinical research focused on the endocrine complications of cystic fibrosis including CF-related diabetes and bone disease. She also serves as a mentor in the CF Foundation EnVision CF Program and Clinical Research Scholars Program.



Michael Schechter, MD, MPH

Faculty

Dr. Schechter is professor and previous chief in the Division of Pulmonary and Sleep Medicine at the Children's Hospital of Richmond (CHOR) at Virginia Commonwealth University and Director of the VCU Cystic Fibrosis Center. Dr. Schechter's research has been primarily concerned with environmental and sociodemographic influences as well as the impact of treatment variations on outcomes in CF. He has served on CF Foundation committees focused on racial justice, food insecurity, and access, as well as the Comparative Effectiveness Research/Registry Committee. He has also worked with the CF Foundation on fostering methods to improve the quality of care and outcomes for people with CF, and with organizations working to improve outcomes for children with other chronic conditions such as Spina Bifida, Inflammatory Bowel Disease, and Sickle Cell Disease. He founded and serves as medical director of the CHOR community asthma program which provides socially aware medical care for low socioeconomic and minority children in the Richmond metropolitan area. Much of his recent work is related to mental health in people with CF. He was co-chair of the CFF Mental Health Taskforce that made recommendations regarding the Foundation's initial efforts in this area, and is currently member of the research subcommittee of the CFF Mental Health Advisory Committee. He is part of a workgroup to make recommendations regarding mental health variable to be added to the CF Foundation Patient Registry, and is co-principal investigator on TIDES2, a study investigating the prevalence and impact of behavioral and mental health problems in pre-school and school age children with CF.

Prior to joining the Virginia Commonwealth University, Dr. Schechter was on the faculty of Wake Forest University, Brown University, and Emory University. He has been an invited speaker at a host of national and interna-

tional conferences, and has an extensive record of published research, reviews, commentaries, edited books and book chapters. He has also served on numerous committees of the American Thoracic Society, and American Academy of Pediatrics (AAP), and is past chair of the AAP Section of Pediatric Pulmonology and Sleep Medicine.

Jennifer Taylor-Cousar, MD, MSCS, ATSF

Faculty

Dr. Taylor-Cousar is a tenured professor of adult and pediatric pulmonary medicine at National Jewish Health (NJH) in Denver, Colorado, where she serves as the Medical Director of Clinical Research Services, Acting Chair of the Department of Pediatrics, Immediate Past President of the Medical Staff, and is co-director of the Adult Cystic Fibrosis (CF) Program and Director of the CF Therapeutics Development Network (TDN) center. She received her undergraduate degree in human biology from Stanford University, and completed her doctorate in medicine, combined residency in internal medicine and pediatrics, and her combined fellowship in adult and pediatric pulmonary medicine at Duke University. She obtained her Master of Clinical Science from the University of Colorado. Dr. Taylor-Cousar's expertise is clinical trial design and conduct; she has been national/global primary investigator on multiple CF TDN pharmaceutical trials. Her investigator-initiated research focuses on the development and evaluation of novel therapies for the treatment of CF, and the long-term impacts of these therapeutics on health outcomes in people with CF; she is currently co-leading the 41-site prospective Maternal and Fetal Outcomes in the Era of Modulators (MAYFLOWERS) study. Beyond her human research, she also is evaluating the etiology and treatment of respiratory disease in orangutans (which have 97% genetic homology with humans). She has published more than 160 manuscripts as well as a book and multiple book chapters. Additionally, she serves/has served on national scientific advisory committees for Emily's Entourage, the Cystic Fibrosis Foundation, American Thoracic Society and the National Institutes of Health. She is an Associate Editor for the Journal of Cystic Fibrosis and a member of the International Advisory Board for the Lancet Respiratory Medicine. Finally, she is currently serving as the Chair of the American Thoracic Society International Conference Committee (2025-2027). Dr. Taylor-Cousar is an elected member of the American Society for Clinical Investigation (ASCI). Her recent awards include the American Thoracic Society's Distinguished Achievement Award (2023,) the American Thoracic Society William J. Martin II Public Advisory Round Table Distinguished Achievement Award (2022), the Emily's Entourage CF Trailblazer Award (2022) and the Cystic Fibrosis Research Incorporated CF Champion Award (2021).

Elizabeth Tullis, MD

Faculty

Dr. Elizabeth Tullis is a Professor of Medicine at the University of Toronto and an Adjunct Scientist at the Keenan Research Centre, Unity Health Toronto. Her interest in cystic fibrosis (CF) was sparked during her Respirology fellowship and further shaped by a clinical CF fellowship in Melbourne, Australia. She is the founding director of the Toronto Adult CF Clinic at St. Michael's Hospital, which currently cares for over 600 adults with CF. From 2014 to 2019, Dr. Tullis held the Cystic Fibrosis Canada Chair in Adult CF Research. She has authored 190 research publications and is currently co-leading the development of Canadian CF Care Guidelines in partnership with Cystic Fibrosis Canada. As a principal investigator, she has contributed to numerous clinical trials, including the pivotal studies on CFTR modulator therapies. Drawing on her extensive experience treating more than 1,000 adults with CF, she has trained 31 CF fellows who now practice worldwide. Dr. Tullis's contributions to CF care have been recognized through multiple honors, including the Queen Elizabeth II Diamond Jubilee Medal, the Dr. Douglas Crozier Award, the Royal College Specialist of the Year Award, and most recently, the King Charles III Coronation Medal in 2025.

Faculty & Steering Committee

Ahmet Uluer, DO, MPH

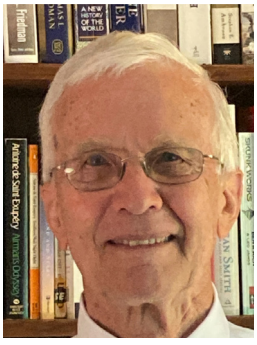
Faculty & Steering Committee

Dr. Uluer is the Director of the Adult Cystic Fibrosis Program and co-Center Director at the combined Boston Children's Hospital and Brigham & Women's Hospital Cystic Fibrosis Center. He is also Director of the Bridges Adult Transition Program at Boston Children's Hospital, providing age-appropriate care and transitional care support to adult survivors of congenital or pediatric acquired chronic illness. His MPH degree from Harvard TH Chan School of Public Health expanded his interests. He became a member of the CF Foundation (CFF) Global Health Advisory Board and received grant support from the CFF to participate in the International Mentoring Training Initiative (IMTI), specifically to establish CF centers in low-middle income countries. His clinical and research interests are focused on preventing and managing complications of people aging with CF. He is a board member of CFRI and among the founding faculty of the CFRI sponsored Patrick Nash Fellows Program, mentoring the next generation of providers to care for the aging CF population. He is also the co-host of 'It's a Lung Story' podcast, which explores the realities of aging with CF in the era of modulators and medical advancements.

Siri Vaeth, MSW

Steering Committee

Siri Vaeth is the Executive Director of the Cystic Fibrosis Research Institute (CFRI). Her involvement with CFRI began in 1995, after her daughter's diagnosis with cystic fibrosis. She served for 10 years on CFRI's Board of Directors before joining the staff in 2013. Siri has a BA in Politics (UC Santa Cruz) and a Master's in Social Welfare (UC Berkeley). Prior to CFRI, Siri was a Head Start social worker, Big Brothers Big Sisters executive director, and Family Advisory Council Lead at the pediatric CF Center at Stanford. She is currently Chair of the American Thoracic Society's Public Advisory Roundtable, and a member of the ATS Student Scholars Working Group. Siri is an active member of several state and national coalitions to advance legislation and policies to improve the lives of those with cystic fibrosis and rare disease.



James R. Yankaskas, MD

Faculty & Steering Committee

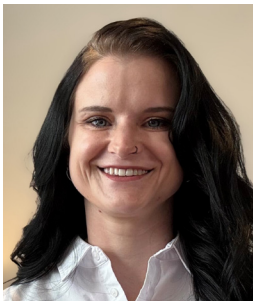
Jim Yankaskas earned his private pilot's license at age 17, received a B.S. in Aeronautics and Astronautics from M.I.T. in 1969, and worked as an Analytic Design Engineer at Sikorsky Aircraft for five years. He then received his M.D. from the University of Connecticut, completed his Internal Medicine residency at UNC and fellowships in pulmonary medicine at Duke University and at UNC-Chapel Hill. He was the inaugural Michael E. Hatcher Distinguished Professor of Medicine at UNC.

Dr. Yankaskas developed the first human CF airway epithelial cell cultures in 1985 and used those to advance research on the mechanisms and treatment of CF lung disease. He helped develop care systems for adults with CF and served on the CF Foundation's Center Committee for 18 years. He led Quality Improvement projects to improve CF care and outcomes across the USA and continues to foster QI for all aspects of CF. He led the UNC Hospitals Medical ICU, pulmonary clinics, and the Lung Transplant program.

CF Adult Speakers

Ashley Ballou-Bonnema, MM - Keynote Speaker

Ashley Ballou-Bonnema, a professional vocalist based in Sioux Falls, SD, received her B.A. from Augustana University and her Masters degree in Music performance from the University of South Dakota. The acting executive director and founder of the 501(c)3 organization, Breathe Bravely, Ashley utilizes her unique experience and expertise as a vocalist to inspire an impact that uses the art of singing to combat the effects of cystic fibrosis. Breathe Bravely's flagship programs, sINgSPIRE and the sINgSPIRE Virtual Choir, utilize the therapeutic and life-giving principles of singing to encourage increased respiratory strength, breath awareness, and breath management skills, all in hopes that those individuals living with progressive lung disease may achieve maximum breath potential. Most of all, the global sIngSPIRE programs are a catalyst for meaningful and empowering connection - dedicated to creating a community in which every voice can find belonging.



Crystal Boeckel

Crystal is a 33-year-old mother of two who recently celebrated her eighth wedding anniversary. She and her family travel the United States full-time for her husband's job. She thrives in her domestic engineering role while also homeschooling both of her children. For most patients, juggling cystic fibrosis is a challenging feat in one location but Crystal best manages her health while constantly on the go. In her spare time, she is an avid weightlifter, hiker, reader, and concert goer.

Joan Finnegan Brooks

Joan Finnegan Brooks was born in the 'dark ages' of cystic fibrosis care and research in 1960. As a rare, older member of the CF community, she is blazing a new trail through CF aging issues! Joan is a tireless advocate and has been a leader in national CF Foundation initiatives for decades focused on CF adult issues, CF-related diabetes, clinical trial participation, patient care and engagement, and quality improvement efforts. She testified before Congress and the FDA, presented at medical conferences, and co-chaired the CF Foundation's successful Peer-to-Peer mentoring program. She proudly serves on Dr. Putman's CFRD Bionic Pancreas Trial Advisory Group. Joan graduated from Brown University and had a career in financial services, followed by a career as a trusted consultant to biotechnology and pharmaceutical companies developing new CF therapies, sharing key insights about the broad CF community.

Joan inspires the CF community with her dedication and determination. Her connection with countless CF families is the touchstone of her life and motivates her work on behalf of this community that she loves so deeply.

Georgia Brown

Georgia Brown lives near Columbus, Ohio. She is trained in public speaking, public relations, and journalism. She applies these skills through her volunteer work, which focuses on sexual and reproductive health and the social determinants of health in individuals with cystic fibrosis. She has served on her CF clinic's Quality Improvement committee since 2018. Georgia also dedicates her time to CFRI through participation in the CF Retreat and the CF Adult Advisory Committees.

Tresse Jean (TJ) Chipres

Tresse Jean (TJ) Chipres was born in 1956. She is a U.S. Navy veteran who also served as a civil servant for the U.S. Army at the Pentagon for 15 years. She received the Commander's Award for Civilian Service for her work in Sensitive Compartmented Information Security. After her medical retirement, she began a career in education at a Catholic school in Alexandria. She retired from that position in 2023. She currently works remotely (part-time) for a technology company as a Federal Programs Manager. TJ has a Bachelor's Degree in Computer Science from University of Maryland (1995) and Master's Degree in Education from George Mason University (2013). In 2019, TJ was diagnosed with CF through gene sequencing at Georgetown University Hospital by Dr. Elizabeth O'Donnell with consultation by Dr. Patrick Flume (MUSC). She is married and has two grown sons.

Alex Gantt

Alex Gantt was diagnosed with cystic fibrosis at nine months old and just turned 40. She lives in Colorado with her husband and their fur babies, two incredibly rambunctious labs. She was born and raised in Austin, Texas, but moved to Colorado about eight years ago to enjoy a world without humidity and to discover what it's like to have four seasons. Alex is an avid reader, and also enjoys camping, jigsaw puzzles, video games, and spending time with her precious nieces and nephews. She is passionate about forming relationships in the CF community and hopes to continue to raise awareness about CF in the general public.

Gordon Dart

At 42 years old, Gord is a devoted husband and proud father to Jake (11) and Brette (9). Born and raised in the GTA (Greater Toronto Area), Ontario, Canada, he has lived with cystic fibrosis his entire life, facing its challenges with strength, resilience, and a deep sense of gratitude - especially for the exceptional care and support he's received from Dr. Tullis and the team at St. Michael's Hospital.

Despite the impact CF has had on many aspects of his life, Gord remains active and engaged. He's passionate about collector cars, loves spending time outdoors walking with the family dog , and has a thrill for speed as an avid go-kart racer. Whether it's navigating the ups and downs of CF or spending time with his family, he brings perseverance, and heart to everything he does.

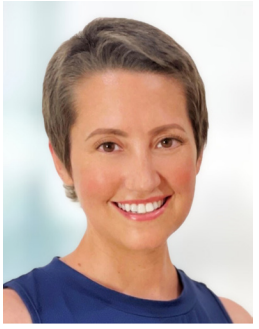
Peter Gianopulos

Peter Gianopulos is a 46-year-old writer, documentarian, husband, father and 4th generation Chicagoan. He was diagnosed with cystic fibrosis at age 4. Despite the challenges of CF - including bouts of severe hemoptysis and an emergency left lobectomy - he pursued his work as a content director and professional writer, including for North Shore magazine, a Chicago Sun-Times lifestyle publication, where he was managing editor. He then launched his own business, as a documentarian and ghost writer. Thanks in large part to the health improvements experienced after taking CFTR modulators, Peter has written more than 15 published books.

Peter spends much of his time working in the field of corporate heritage, where he works with CEOs and cor-

CF Adult Speakers

porate communicators to use organizations' unique histories to write corporate history books, curate museum exhibits, design digital tools and lead long-form oral history projects. Peter dreams, one day, of sitting down and capturing the stories and reflections of CF patients, doctors, researchers, advocates so that advances made during this critical epoch in CF care are not only documented but can inspire others fighting equally challenging battles. In between projects, he has enjoyed teaching journalism and communications as an adjunct professor at Loyola University Chicago, while continuing to hone his passion for home cooking and working as an advocate for helping patients (and their caretakers) who live with chronic medical conditions.



Colleen Lewis

Colleen is an adult with cystic fibrosis and a breast cancer survivor. She owns and operates a thriving dog boarding business in Philadelphia, where her love for animals shines through in the personalized care she provides. Colleen teaches yoga classes for the CF community, when her mind and body allow, through CFRI and CF Yogi. Outside of work, Colleen enjoys hiking with her dogs and tending to her rose garden, blending her love for nature with her usually active lifestyle. She's currently in a phase of recovery and rest. Find her on Instagram @calminphilly

Stephen McParland

I was born on December 15, 1949 in South Boston, Massachusetts. I was the third child of my parents, Charles A. and Mildred F. McParland. My parents' first child (Joey) was born in 1946 and died in 1948. He was being treated for pneumonia and though undiagnosed, it was later assumed that he died of CF. My brother, Gerard, was born in 1948 and was born healthy. When I was born, my parents saw in me the same symptoms as Joey and brought me to Boston Children's Hospital in February 1950, where I was treated for the next 34 years by Dr. Harry Shwachman. My sister, Doris, was born in 1953 and was healthy. My brother Charlie was born in 1957 and died in 1981 of CF. My genetic make-up is Del508 homozygous. I have been very fortunate in my CF treatment. I have had a healthy regimen for the past 40+ years focused on diet and exercise. I participate in as many research studies for CF that I qualify for.

I am a graduate of Boston College, Class of 1971. I am a CPA by training and have worked in the real estate business since 1980. Today I am semi-retired and live on Cape Cod and spend winters in Indian Wells, California. My wife and I are avid golfers and spend a great deal of time traveling.

Brent Pace

Brent Pace was diagnosed with cystic fibrosis in 1978 at the age of three when his younger brother was diagnosed at birth. Brent recently celebrated his fiftieth birthday with a weekend of activities enjoyed with friends including playing a four and a half hour rock concert. Having lived with CF for half a century, he has been witness to and a recipient of many medical achievements and breakthroughs. He has been a participant in numerous research studies and trials thereby being an active part in moving science and medicine forward for the CF community. He has raised over $500,000 for the Cystic Fibrosis Foundation which has been a leader in fighting for CF patients and finding a cure. While Brent is greatly benefiting from the incredible drug Trikafta, he remains focused on supporting the foundation to find more therapies and treatments for all patients with cystic fibrosis.

Brent has worked for BP as an engineer for over 30 years helping to improve renewable energy sources. He lives in Charleston, South Carolina, with his wife Christine.

CF Adult Speakers

Peter Sengelmann

Peter Sengelmann, 38, lives with cystic fibrosis. Born in North Carolina and raised in Portland, Maine, he later moved west to attend college in Denver, CO, where he still resides today. Peter wasn't diagnosed with CF until 2019, when he and his wife were struggling with infertility. Genetic testing ultimately led him to the CF clinic at National Jewish Health in Denver, where he received his official diagnosis.

Professionally, Peter has built a successful career as a commercial real estate broker, with more than 13 years of experience in the industry. On a personal level, he and his wife recently welcomed two children - a daughter in February 2022 and a son in April 2025 - after a long seven-year journey through IVF. In his free time, Peter enjoys skiing, mountain biking, golfing, and fly fishing throughout the mountains of the West.

Steven Yankopoulos

Steve was diagnosed with cystic fibrosis at 36 hours old at Boston Children's Hospital, and was diagnosed with *B. delosa i*n 2004. He is one of about 10-15 (0.5% of the CF community) who culture this bacteria. He's no stranger in public spaces. Having had over 3,500 doctor appointments since 2001, and 800 nights in the hospital, he has lectured at over 10 colleges, – including Harvard, MIT, Boston College, and Boston University – to nursing students, medical students, and psychology students, about everything medical field related, including sharing stories and personal experiences of what it's like to have a chronic illness, and what it takes to become great as a doctor/nurse. More recently, he's spoken with the Mass General Hospital diabetes research team and Research Con 2025. He has run three Boston Marathons to support the CF Foundation. His biggest accomplishment is helping to establish the National Basketball League of Canada, owning a professional team, and utilizing his platform and fame in Canada to raise awareness for CF. He currently hosts a podcast called Chronically Unheard and is using his business background to help build a new era of medicine, examining it from all aspects.

Fellows

Emma Albert-Stone, MD

Emma is a second year pulmonary and critical care medicine fellow at Brown University. Prior to fellowship, she completed a combined internal medicine and pediatrics residency at the University of Michigan where her interest in cystic fibrosis started. She has an interest in improving transitions of care from pediatrics to adulthood for patients with CF. In her spare time she enjoys spending time with family and friends, exploring new restaurants, and playing ultimate frisbee.

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Linto Antony, MS, PhD

Linto Antony is a postdoctoral scholar at the Cystic Fibrosis Research Center at the University of Alabama at Birmingham. He completed his master's degree and a PhD in Biological Sciences from South Dakota State University, where his research focused on the gut microbiome and host-microbe interactions. During his time at UAB, he received a two-year RDP trainee fellowship from CFRC at UAB to study novel anti-inflammatory therapeutic strategies for CF. After completing his postdoctoral training, he plans to become an independent researcher and contribute to understanding and developing treatments for cystic fibrosis, with an interest in addressing infection and inflammation in people with CF.

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Taylor Baumann, MD

Taylor Baumann is a combined adult and pediatric pulmonology fellow at Boston Children's Hospital and Brigham & Women's Hospital. His clinical focus is cystic fibrosis, bronchiectasis, and rare pulmonary genetic diseases. At the Channing Division of Network Medicine at Harvard, he is building longitudinal cohorts of patients with bronchiectasis to study genetic and environmental factors that influence disease progression. He is also pursuing an MPH in Quantitative Methods at the Harvard School of Public Health to strengthen his research in precision medicine and improve outcomes for patients with CF and related conditions.

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Jazmin Calyeca, MS, PhD

I am a Scientist at the Center for Regenerative Medicine, Nationwide Children's Hospital, advancing translational research in airway and lung under both physiological and fibrotic conditions. I earned my PhD in Biological Science and Biomedicine from the National Autonomous University of Mexico (UNAM) and completed postdoctoral training at the University of Pittsburgh and The Ohio State University, focusing on cellular and molecular mechanisms of tissue repair. My research goal is to accelerate the development and translation of therapies to clinical practice leveraging omics approaches. Currently, I am involved in preclinical projects aimed at enhancing treatments for children with airway defects by developing and applying tissue engineering and computational methods. My current research investigates the biological responses to airway surgery (surgery-induced stress) through integrative omics, tissue

engineering, and molecular biology approaches, with an emphasis on epithelial plasticity, cell–matrix interactions, and fibroblast heterogeneity to address repair mechanisms in cystic fibrosis.

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Gretchen Goble, MD

Dr. Gretchen Goble is a first year pulmonary and critical care fellow at Washington University School of Medicine in St. Louis. She completed her internal medicine and pediatrics combined residency program at Indiana University after attending medical school at SUNY Upstate Medical University in Syracuse, NY. Throughout residency, she participated in quality improvement in multidisciplinary care regarding access to colorectal cancer screening for people with CF. Her clinical and research interests include CF, non-CF bronchiectasis, and chronic lung diseases that span the transition from childhood to adulthood. She is passionate about expanding access to pulmonary and critical care services globally, especially for refugee and immigrant populations from diverse cultural and linguistic backgrounds.

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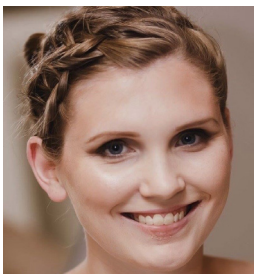

Claire Haglund, PhD, LMSW-C, MMT

Claire Adeline Haglund, PhD, LMSW-C, MMT, graduated with her doctorate in clinical social work from the Institute for Clinical Social Work. Her research has focused on fostering the psychological well-being of those living with chronic and terminal illness, the utilization of trauma-focused cognitive behavioral therapy with inner city residing family systems, and the application of music therapy as pain management with the terminally ill. She has also created and co-published various assessment tools for interdisciplinary health care, court, and child welfare teams. Currently, she works as the Cystic Fibrosis clinical social worker at the Children's Hospital of Michigan. In that role, she has helped build a transition program with adult care centers around the nation, cofounded (alongside her fabulous CF Nurse Coordinator) a mentoring program with the Bonnell Foundation, and is actively involved with her chapter's CF Foundation. She has also been involved in multiple interdisciplinary teaching and training roles with medical students and nursing staff as it relates to diabetes, grief and loss, gun violence, and sexual abuse assessment. Outside of CF care, she has a private practice, serves as a music therapist with area hospice agencies, and is also an assistant professor at several universities, where she was named top research social work faculty for 2025.

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Sarah Haroon, MD

Sarah Haroon, MD, is an Assistant Professor of Endocrinology and Mineral Metabolism at UT Southwestern Medical Center. She specializes in osteoporosis and menopause in cystic fibrosis. Dr. Haroon earned her medical degree at Aga Khan University Medical College in Karachi, Pakistan. She completed an internal medicine residency at Beaumont Hospital in Royal Oak, Michigan. She gained advanced training through a fellowship in endocrinology at the Medical College of Wisconsin in Milwaukee. She also completed a fellowship at the MacLean Center for Clinical Medical Ethics at the University of Chicago. Certified by the American Board of Internal Medicine, Dr. Haroon joined the UT Southwestern faculty in 2023. Dr. Haroon's specific interests in cystic fibrosis are understanding the influence of menopause on bone health, efficacy and safety of menopausal hormone therapy (MHT) for menopausal symptom management, as well as impact of MHT on bone health.

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Fellows

Rory Lubner, MD

Rory Lubner is a Rhinology/Endoscopic Skull Base Surgery fellow at the University of California, Los Angeles (UCLA), where he is pursuing advanced training in complex sinonasal and skull base disorders. He earned a Bachelor of Science (BS) with Distinction in Neuroscience from Duke University and his medical degree (MD) from Brown University. Dr. Lubner went on to complete his residency in Otolaryngology–Head and Neck Surgery Vanderbilt University Medical Center from 2020-2025.

At UCLA, his fellowship has focused on advanced endoscopic/skull base techniques, revision sinus surgery, and the multidisciplinary care of patients with refractory chronic rhinosinusitis. With a robust CF Center, he is also seeing and treating many CF patients as a part of a multidisciplinary team. He plans to pursue a career in academic medicine, and is passionate about combining clinical excellence with collaborative, patient-centered care. Through the Patrick Nash Fellows Training Program, he aims to deepen his expertise in the multidisciplinary management of cystic fibrosis, advance research in sinonasal manifestations of the disease, and prepare for a career dedicated to caring for this complex patient population.

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Sarah MacDowell, MD, MPH

Sarah is currently a clinical instructor at The Ohio State University in Columbus, OH, having just completed Pulmonary and Critical Care fellowship. Prior to fellowship, she completed a combined internal medicine-pediatrics residency at The Ohio State University/ Nationwide Children's Hospital, as well as a Clinician Educator fellowship also at The Ohio State University. She currently works in the laboratory of Dr. Daniel Wozniak, supported by the Cystic Fibrosis Foundation, studying *Pseudomonas aeruginosa* biofilms and the development of novel therapeutics against them, including bacteriophage therapy. Clinically, she is interested in the management of cystic fibrosis and non-CF-related bronchiectasis as well as the transition of those with cystic fibrosis and other chronic pulmonary conditions from pediatric to adult care.

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Mostafa Mostafa, MD

Dr. Mostafa M. Mostafa is an Andrology Fellow at the University of Illinois at Chicago, where he is pursuing advanced training in male reproductive health and microsurgical techniques. Originally from Egypt, he completed his medical training there before moving to the United States to further his career in academic urology.

His clinical and research interests center on male infertility, surgical innovation, and improving patient outcomes through minimally invasive techniques. He is passionate about bridging clinical care with research to expand treatment options for patients.
Outside of medicine, Dr. Mostafa enjoys watching and playing soccer, running, and spending time with his family.

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Fellows

Melissa Ross, MD

Melissa is a second year Adult Pulmonary and Critical Care fellow at Northwestern University. Prior to fellowship, she completed medical school at Duke University SOM followed by Internal Medicine and Pediatrics residency at University of Michigan. Her research interest is in the long term impacts of pediatric medical interventions on lung health in adults with CF, particularly at the intersection of CF and prematurity. Outside of work, Melissa enjoys exploring Chicago's many vibrant neighborhoods, planning her next national park adventure, cheering for Duke basketball, and spending quality time with her family and friends.

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David Schreier, PhD

I work in Dr. Hara Levy's lab at the University of Wisconsin-Madison School of Medicine as a molecular biologist. I completed my PhD in biomedical engineering from the University of Wisconsin-Madison. Our lab focuses on understanding the genomic basis of cystic fibrosis (CF), mainly focused on CF lung disease severity and therapeutic response in children and adults with CF and carriers (parents and siblings). I use bioinformatics, focusing on the epigenetic and epigenomic changes of peripheral blood mononuclear cells and neutrophils in children and adults with CF. Utilizing sequencing techniques such as bulk and single cell sequencing and subsequent analysis, the results have demonstrated links between metabolism and immune function in adults with CF. We continue our research with the primary interest in nuclear architecture (derived from CUT&RUN sequencing) and the interplay of gene expression with coding and noncoding RNA (obtained through bulk and single cell sequencing) in CF, as it relates to airway infections and understanding of molecular underpinnings of trained immunity. Our goal is to more precisely define a targeted clinical course and treatment response unique to children and adults afflicted with CF, in addition to modulator therapy.

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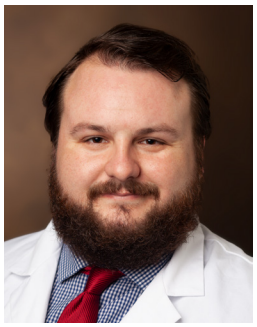

Justin Smith, MD

Justin is a second year adult pulmonary & critical care medicine fellow at Brigham and Women's Hospital where he also serves as a fellow in the adult cystic fibrosis program at Brigham and Women's/Boston Children's Hospital. Prior to this he completed a combined residency in internal medicine and pediatrics at Vanderbilt University Medical Center and medical school at the University of Tennessee Health Science Center. His clinical and research interests include adolescents and young adults with chronic lung disease, transitions of care for patients with CF, long-term sequalae of pediatric lung disease, and the unique experience of young adults admitted to adult intensive care units.

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Fellows

Danai-Christina Theiopoulou, MD, MSc

Danai earned her Medical Degree from the University of Crete, followed by a Master of Science in Rheumatology-Musculoskeletal Health from the National and Kapodistrian University of Athens. Having been a volunteer researcher at Massachusetts General Hospital (MGH) for over three years, she contributed to an innovative pediatric lung function study in Uganda, aimed at improving respiratory care in underserved communities. Additionally, Danai has gained experience in regulatory affairs, broadening her understanding of healthcare through the pharmaceutical industry perspective. Most recently, she accepted a Post-Doctoral Research Fellowship at MGH, where she will focus on advancing treatment for children with asthma. Eager to expand her knowledge and apply her interdisciplinary background, Danai aims to help individuals with CF live longer, healthier lives.

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Hayrettin Yavuz, MD, PhD

Dr. Hayrettin Yavuz, MD, PhD, is a postdoctoral researcher in the Department of Pediatrics at the University of Virginia, working under the mentorship of Dr. Agnieszka Swiatecka-Urban. He earned his MD in 2015 and completed his PhD in Biochemistry in 2022. Dr. Yavuz's research focuses on the molecular and clinical aspects of cystic fibrosis (CF), with a particular interest in early detection of kidney injury and the role of extracellular vesicles (EVs) as biomarkers in CF-related complications. His current work combines advanced biomarker analysis with translational approaches to better understand CF comorbidities, particularly CF-related kidney disease (CFKD).

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Abstracts

History and Development of Adult CF Care

James Yankaskas, MD

Presented at Pre-Symposium on Tuesday, September 9

Science and the practice of medicine continually evolve. New techniques and improved practices lead to better outcomes over time. Cystic fibrosis illustrates those items well. When CF was first described in 1939, it led to death in infancy. Physicians and scientists worked to improve knowledge and care since then. Adult CF care programs were recognized in 1980 and contributed greatly to that progress. The median predicted survival improved steadily and by 2013, there were more affected adults than children with CF in the U.S. Those developments help provide the basis for further progress in CF knowledge, care, and patient life.

Introduction to Becoming Part of a CF Care Center

Whitney Brown, MD

The impact of aging is different for every individual with CF and varies based on many factors such as age, health status, modulator status, lived experience, and expectations for the future. This session will feature and integrate the perspective of an adult who was diagnosed with CF later in life on aging with CF. The structure of the CF care team and the expanding number of health professionals that may participate in the care of people with CF over a lifetime will be discussed. Next, an overview of the CF Foundation Patient Registry will be provided, including a sneak peek at data from the newly created "Aging with CF" Chapter that will be part of the 2024 Annual Data Report to be published in October 2025. Lastly, the process to submit a registry research data request to CF Foundation Patient Registry will be shared and encouraged as we seek to describe and understand the aging CF population.

Socioeconomic Considerations for Adults Aging with CF

Michael Schechter, MD, MPH

There is great variation in CF outcomes, caused by the interaction of genetic determinants with environmental exposures which are impacted by different healthcare interventions. The social determinants of health (SDOH) include the conditions in which people are born, grow, work, live, and age. Socioeconomic status (SES) is a more limited construct that is typically measured by wealth, education, occupational status. The strong effect of SES on CF outcomes has been established by observational research conducted over the last 30 years in the US and Europe and can be seen within countries and also across countries of different GDP. The mechanism by which low SES impairs health is primarily by way of increasing exposure to adverse environmental exposures and, probably to a lesser degree for people with CF (PwCF) than for the general population, in reducing access to and utilization of healthcare interventions.

Environmental exposures can include physical (e.g. tobacco smoke), psychological (e.g. stress, leading to an increase in mental health disorders) and financially induced shortages of necessities such as food and housing. The expenses involved in CF care take a great toll on quality of life for PwCF. Access to healthcare is nominally equal across SES strata (except for the relatively small number of CF patients who are uninsured, and except for transplant referral practices), but decreased medical literacy and decreased self-efficacy often combine to impair disease self-management. While some adverse SDOH are embedded in our social structure and not immediately remediable by the healthcare team, the presentation ends with a dicussion of those that can be screened for and intervened upon.

Abstracts

Aging in the Era of Highly Effective CFTR Modulators: A New Frontier in CF Care

Manu Jain, MD

With the arrival of highly effective CFTR modulators, cystic fibrosis is no longer solely a disease of children and young adults - it is a lifelong condition with continually growing adult population. As people with CF live longer, we face new questions about how to preserve health, prevent complications, and address the unique challenges of aging in people with CF. This session will explore what it means to grow older with CF, from the biology behind modulators to strategies that extend not just life, but quality of life.

Learning Objectives

Describe CFTR genotypes and protein biology driving modulator efficacy
- Efficacy and Tolerability Data (ETI and Alyftrek)
- Heterogeneity (within and across genotypes)
- Comparative prescribing profile for approved and investigational modulators

Describe the demographic shift in CF with the advent of highly effective CFTR modulators (HEMTs)
- Review current survival trends and projected life expectancy
- Compare historical and contemporary age distributions in CF populations
- Contras Healthspan versus Lifespan

Understand the long-term physiological impacts of HEMTs on multisystem disease in aging individuals with CF
- Summarize evolving patterns of pulmonary, pancreatic, hepatic, and gastrointestinal disease (More detail in subsequent sessions)
- Discuss renal, cardiovascular, bone health, and metabolic implications of prolonged HEMT use

Identify emerging age-related comorbidities and their intersection with CF-specific pathophysiology
- Explore risks of malignancy, cardiovascular disease, diabetes, osteoporosis, and cognitive decline
- Potential impact of continued inflammation and metabolic abnormalities
- Review evidence and gaps in screening and surveillance practices

Review the challenges and opportunities in clinical care delivery for older adults with CF
- Define models of comprehensive, age-appropriate multidisciplinary care
- Consider geriatric principles in CF care planning

Explore research priorities and knowledge gaps in the context of aging with CF on HEMTs
- Identify critical questions in longitudinal outcomes, drug safety, and phenotypic evolution
- Discuss the importance of real-world data, registries, and geriatric-CF collaborations

Increased Risk of GI and Other Cancers in People with CF

Steven Freedman, MD, PhD

With advances in the care of patients with CF have come new challenges. As people with CF age, we are seeing the emergence of an increase in cancers. These are concentrated on the GI tract, but other cancers are seen as well including breast and cervical cancer. The reason for the increased cancer risk in CF is not known but a number of factors predispose.

First, CFTR itself is an anti-oncogene (tumor suppressor). A study published in Immunity in 2017 by Dr. Alice Prince's group has shown that CFTR interacts with the tumor suppressor PTEN to activate PI3 kinase, regulate the inflammatory response and activate host defenses against *Pseudomonas*. With loss of CFTR function, loss of PTEN leads to a pro-oncogenic and hyperinflammatory state along with impaired *Pseudomonas* clearance.

Other predisposing factors for GI tract cancers include the high saturated fat diets, the gut dysbiosis, altered GI transit times, and chronic GI inflammatory state, which are all linked to an increased risk of colorectal cancer. For pancreatic cancer, diabetes is a risk factor and thus taken together along with the loss of CFTR tumor suppressor function, we have a perfect storm for the development of malignancy.

A number of questions remain: Will CFTR modulators have a protective effect on malignancy? Can we attenuate risk with a 'healthier' diet? Is the biologic behavior of tumors in CF more aggressive? How do we screen for malignancies with the least invasive procedures? Should we treat cancers in people with CF similar to non-CF patients?

Mental Health Considerations for Adults with CF

CJ Bathgate, PhD

Adults with cystic fibrosis (CF) face unique mental health (MH) challenges that extend beyond depression and anxiety. While modulators have improved physical health and quality of life for many, emerging evidence highlights potential neuropsychiatric side effects, such as mood changes, cognitive difficulties, and psychological distress, that could be linked to direct drug effects, drug–drug interactions, or secondary psychosocial factors. This presentation integrates patient perspectives, provider observations, and current research to explore the prevalence and complexity of MH comorbidities in adults with CF, including medical traumatic stress. Neurobiological findings suggest possible mechanisms through CFTR expression in the brain and off-target drug effects. Evidence-based interventions, such as CF-specific cognitive behavioral therapy, stress management, acceptance and commitment therapy, and trauma-focused approaches, are discussed alongside traditional medication management. By highlighting lived experiences, clinical data, and therapeutic strategies, this work underscores the importance of proactive, individualized MH care as an essential component of comprehensive CF management.

NTM Infections in Cystic Fibrosis

Elaine Cagnina, MD, PhD

Non-tuberculous mycobacterial infections are a unique group of pulmonary infections with increased prevalence in adults living with CF. This talk will aim to introduce and define this class of infections, describe the specific challenges in both diagnosis and treatment in adults with CF, and discuss the current state of research in this area.

Endocrine Complications in the Aging CF Population: CF-Related Diabetes

Melissa Putman, MD, MMSc

As people with CF live longer in the post-modulator era, the prevalence of endocrine complications of CF will likely continue to rise. CF-related diabetes (CFRD) affects up to 40% of adults with CF and has been associated with a significant decline in pulmonary function and nutritional status. The recommended treatment for CFRD is insulin therapy, which has been shown to improve CF specific outcomes but also adds substantial treatment burden. At the same time, the rising rate of overweight/obesity since the introduction of elexacaftor/tezacaftor/ivacaftor is changing the CFRD phenotype by causing increased insulin resistance and metabolic syndrome, which is also raising the possibility of non-insulin therapies for the treatment of CFRD.

Abstracts

CF Airways Infection: That Was Then and This Is Now Antimicrobial Management in CF

Patrick Flume, MD

Persistent infection of the airways has been a hallmark of CF lung disease. Opportunistic bacteria are able to establish residence in the airways, progressing over time, and associated with worse clinical outcomes. The host response to these bacteria is excessive and causes injury to the airways resulting in daily symptoms (e.g. cough, sputum production), intermittent pulmonary exacerbations (i.e. acute clinical worsening of signs and symptoms), and progressive loss of lung function. Tactics to address this infection have included antibiotics to prophylax against infection, eradication of new pathogens, and suppression of infection, all in the hopes of improving symptoms and reduce exacerbations. In this session we will review our knowledge of infection in the CF airways and the evidence to support current practices. We will also address how the advent of CFTR modulators has impacted our understanding of airways infection and what novel questions need to be addressed.

Endocrine Complications in the Aging CF Population: CF-Related Bone Disease

Melissa Putman, MD, MMSc

CF-related bone disease has a rising incidence with age, affecting roughly 30-60% of adults with CF over age 30 years. Osteoporosis and fractures can lead to significant morbidity in people with CF, particularly rib and vertebral fractures. Multiple risk factors may contribute to compromised bone health in CF, including vitamin D deficiency, pancreatic insufficiency, malnutrition, inflammation, glucocorticoid treatment, pubertal delay and hypogonadism, and reduced weight-bearing activity. With the aging CF population, we will likely see an increase in the number of women entering menopause, which is associated with a rapid decline in bone density and high rate of fracture. More research is greatly needed to understand the impact of aging on the endocrine complications of CF.

Cardiovascular Disease: Modulator and Non-Modulator Associated Hypertension, Obesity, CFRD

Ahmet Uluer, DO, MPH

Cardiovascular disease (CVD) is an emerging complication for individuals with chronic conditions, including those aging with cystic fibrosis (CF). As life expectancy for people with CF continues to increase, there is a growing need to identify and address modifiable CVD risk factors such as atherosclerotic heart disease and heart failure. The progression of atherosclerosis may be accelerated in CF due to chronic systemic inflammation and disease-specific factors, including cystic fibrosis–related diabetes (CFRD), hypertension, obesity, and dyslipidemia. Increased oxidative stress further promotes early vascular damage. Recent advances in CF treatment, particularly with CFTR modulators, have markedly improved pulmonary function and overall quality of life. However, these therapies primarily target respiratory health and may not directly reduce cardiovascular risk, underscoring the importance of dedicated monitoring and prevention. Primary prevention during adolescence and early adulthood offers an opportunity to mitigate inflammation, manage risk factors, and delay the onset of atherosclerosis. Routine screening for hypertension, CFRD, dyslipidemia, and other risk factors, combined with early intervention and aggressive management, should be integrated into the comprehensive care models already familiar to CF centers. Just as proactive care has reduced pulmonary and nutritional complications, a similar focus on cardiovascular health could extend survival and improve quality of life for adults with CF.

Sleep Disturbances in CF

Elizabeth Tullis, MD

Emerging evidence suggests that CFTR plays a critical role in the regulation of circadian rhythms, with CFTR dysfunction implicated in sleep disturbances, particularly delays in sleep phase consistent with circadian rhythm disruptions. Sleep dysfunction in cystic fibrosis (CF) is multifactorial, driven not only by intrinsic genetic factors but also related to common clinical symptoms such as chronic cough, nasal congestion and rhinosinusitis, gastroesophageal reflux, pain, and psychological factors including anxiety and depression. Additionally, the use of medications such as opioids and marijuana may further exacerbate sleep problems.

Sleep disturbances are prevalent among both children and adults with CF, encompassing poor sleep quality, insomnia, and restless legs syndrome. Moreover, sleep-disordered breathing (SDB), particularly obstructive sleep apnea (OSA), is more frequent in the CF population, including pediatric patients. Despite the recognized burden of sleep issues in CF, the impact of CFTR modulator therapies on sleep quality and SDB remains unclear, with current studies reporting variable and sometimes conflicting outcomes.

Notably, there are currently no standardized guidelines for screening sleep-related issues in people with CF (pwCF). This gap underscores the urgent need to develop and validate effective screening tools specifically tailored to detect sleep disturbances and SDB in this population. Early identification and management of sleep problems could improve quality of life and potentially impact disease outcomes in pwCF.

Phamaceutical and Pharmacological Implications in CF and Aging

Alexander Philbrick, PharmD, BCPS

Cystic fibrosis is a chronic disease affecting many organ systems, and pharmacologic interventions are an elegant solution for managing the myriad complications caused by CF. CFTR modulators represent an evolution in CF care, resulting in significantly improved survival and quality of life. As patients age, non-CF-related pathologies will manifest more commonly and may likely require additional pharmacologic management. Polypharmacy and drug interactions are common in this patient population, and if left undetected they can have a deleterious impact on long-term patient outcomes. This session will discuss strategies for optimizing efficacy and risk mitigation including pharmacogenomics, therapeutic drug monitoring, as well as considerations for many other commonly used medications (e.g., proton pump inhibitors, SSRIs, etc).

Reproductive and Sexual Health

Jennifer Taylor-Cousar, MD, MSCS

The absent or decreased chloride and bicarbonate transport that adversely impacts the lung, gastrointestinal tract, pancreas and liver in people with cystic fibrosis (CF) also affects fertility. Approximately 98% of males with CF are infertile due to congenital bilateral absence of the vas deferens (CBAVD). However, males with CF are not sterile as the majority will still have functional sperm in the testes. Parenthood, if desired, is possible through assisted reproduction techniques.

While most males with CF are infertile, most females with CF are able to become pregnant if desired. In the era prior to widespread use of CF transmembrane conductance regulator (CFTR) protein modulators, approximately 35% of females with CF had subfertility (challenges becoming pregnant without assistance), but for those eligible and able to take CFTR modulators, evidence suggests fertility is increased likely because of improved overall health and the direct action of CFTR modulators on CFTR function in the cervix and uterus. There are ongoing large, multicenter studies assessing the impact of pregnancy and parenthood on the physical and mental health of people with CF.

About CFRI

The Cystic Fibrosis Research Institute (CFRI) is a 501(C)(3) organization that funds innovative CF research and offers education, advocacy and psychosocial support programs and services to those with CF, as well as their families and caregivers.

Our **mission** is to be a global resource for the cystic fibrosis community while pursuing a cure through research, education, advocacy, and support. Our **vision** is to find a cure for cystic fibrosis while enhancing quality of life for the CF community.

When CFRI was founded in 1975 by a small group of CF family members, children with CF were not expected to survive their teen years. Initially a volunteer-run organization focused on research, CFRI responded to the CF community's needs and expanded its programs to include educational and support programs. Today, CFRI provides a wide range of services to meet the multi-faceted needs of our national and international CF community.

Education

- 39th Annual National CF Education Conference: July 24 - 26, 2026 - renowned experts in the field of CF, patient panelists, and CF researchers present the latest in research and clinical practice to in-person and virtual attendees
- Weekly eNews: updates on CF research, special events, advocacy efforts, and support programs
- *CF Community Voices*: podcast series by and for the CF community
- Newsletters: Twice annual printed *CFRI Community* and Spanish-language *CFRI Comunidad.*
- Website, Facebook, Twitter and Instagram: dynamic resources for the global CF community

Support

- Support Groups: nine virtual facilitated groups provide peer-to-peer support to our diverse community (adults with CF, caregivers, those ineligible for modulators, Spanish-speaking CF community members, etc.)
- Counseling Support Program: financial support for six individual counseling sessions for people with CF and their family members
- Community Retreats: virtual and hybrid Retreats for adults with CF; and in-person and virtual Retreats for mothers of children/adults with CF
- Online Mindfulness Meditation Workshops provided by Julie Desch, MD, an adult living with CF
- CF Wellness: free weekly online CF-specific wellness classes, including strength training, yoga, Pilates, dance, flexibility and stretching

Advocacy and Awareness

- Many Voices ~ One Voice CF Advocacy and Awareness Program: broadens understanding of the physical, emotional, and financial challenges faced by the CF community while advocating to reduce barriers to medical care and therapies and increase investment in research
- Faces of CF Diversity & Inclusion Program: CF impacts people of every race and ethnicity. This program advances awareness of our CF community's diversity, while creating resources – including podcasts and brochures - for underrepresented groups.

Research

CFRI is providing grants to researchers at the following institutions. Much of this research will benefit all those living with CF, regardless of their CFTR mutation.

New Horizons Award Program

- Ashley Cooney, PhD - University of Iowa
- Daria Van Tyne, PhD - University of Pittsburgh
- Ruobing Wang, MD - Boston Children's Hospital
- Daniel Wolter, PhD - University of Washington
- Feng Yuan, PhD - University of Iowa

Elizabeth Nash Memorial Fellowship Program (For Post-Doctoral Fellows)

- Paul Bollyky, MD, PhD; Samuel Rodriguez-Perez, PhD, MS - Stanford University
- Steven Jonas, MD, PhD; Ruby Sims, PhD - University of California Los Angeles
- Ron Kopito, PhD; Celeste Riepe, PhD - Stanford University
- Sriram Vaidyanathan, PhD; Brodie Ranzau, PhD - The Research Institute at Nationwide Children's Hospital
- Katrine Whiteson, PhD; Sage Dunham, PhD - University of California Irvine

Letters of Intent for the 2026-2028 funding cycle are being accepted until November 3, 2025. For information about any of these programs, please email cfri@cfri.org, or go to www.cfri.org.

About the Elizabeth Nash Foundation

The Elizabeth Nash Foundation was established in 2003 by her family to honor and perpetuate Liz's lifelong example of giving and to continue her fight against cystic fibrosis. During her lifetime Liz fought CF as a PhD research scientist, Chair of the Research Advisory Committee for Cystic Fibrosis Research Institute, and as a mentor to teens with CF. The foundation focuses its investments in two areas:

- Scholarships to assist people with CF who are pursuing undergraduate or graduate degrees, and
- Cystic fibrosis research via support of CFRI's Elizabeth Nash Memorial Fellowship for Post-Doctoral Research in CF

The foundation is particularly interested in new research initiatives that improve the quality of life and outcomes for adults with CF.

The Elizabeth Nash Foundation is a donor-supported 501(c)3 non-profit public benefit charity. Donations are tax deductible, and 100% of funds raised go to programs and benefits for individuals with CF.

Website: https://www.elizabethnashfoundation.org/

CFRI Cystic Fibrosis Research Institute

RESEARCH · EDUCATION · ADVOCACY · SUPPORT

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