

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





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Welcome

Dear Friends,

On behalf of the Steering Committee, it is my 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. We welcome the first cohort of 16 fellows to this inaugural symposium that will focus on the multi-organ impacts of CF. Fellows represent 15 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 shar-

ing 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.

Members of the Steering Committee 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,

Siri Vaeth, MSW Executive Director

Symposium Schedule

Thursday, November 7

4:00 pm Welcome & Introduction to CFRI

Siri Vaeth, MSW

Symposium Mission & Aims

Overview: Aging in CF Ahmet Uluer, DO, MPH

4:30 pm Keynote Address

Emily Schaller

5:15 pm **Icebreakers / Introductions**

Carolyn Nash

6:15 pm **Dinner**

Friday, November 8

7:45 am **Breakfast**

8:30 am Epidemiology and the Changing CF Demographic and Challenges

Whitney Brown, MD

Joshua Hillman; Maureen Kahr

9:30 am Increased Risk of GI and Other Cancers in People with CF

Steven Freedman, MD, PhD

Anna Payne

10:30 am Break

10:45 am **Lung Transplant for Cystic Fibrosis**

Joseph Pilewski, MD

Bret Ambrose

11:45 pm **Lunch**

1:00 pm Endocrine Complications in the Aging CF Population

Melissa Putman, MD, MMSc

Joan Finnegan Brooks

Friday, November 8 (continued)

2:00 pm Cardiovascular Disease: Modulator and Non-Modulator Associated

Hypertension, Obesity, CFRD

Ahmet Uluer, DO, MPH Alexandra Rosado

3:00 pm Break

3:15 pm Modulator Benefits, Complications and Implications on Aging

Deepika Polineni, MD, MPH

Ed Canda, PhD

4:15 pm Career Development & Mentors

James Yankaskas, MD

5:15 pm **Break**

6:45 pm **Dinner and Discussion** (Coohills Restaurant)

Saturday, November 9

8:15 am **Breakfast**

8:45 am **Breath Exercise**

9:00 am **Reproductive and Sexual Health**

Jennifer Taylor-Cousar, MD, MSCS Crystal Boeckel; Max Winkler

10:00 am Some Immunological Aspects of CF in the Aging Patient

Richard Moss, MD Abhijit Tirumala

11:00 am **Break**

11:15 am The Path Forward

Key Takeaways

• Hot Topics for Further Exploration

• Post-Symposium Activities / Sharing

Ahmet Uluer, DO, MPH

Richard Moss, MD

12:30 pm **Symposium Ends**



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.



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 across 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 man-

agement support and grant writing tools to enhance the transition from an NIH K to Ro1 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.



Richard Moss, MDFaculty & 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 is the Senior Vice President and Chief Operating Officer at Red Hat, Inc., where she previously served as Chief Financial Officer. As a dynamic leader, Carolyn builds and retains diverse, high-performance teams by hiring, developing, and motivating skilled professionals. She brings extensive expertise in financial and operational management, Al/data analytics, risk management, and organizational strategy. Carolyn is a committed advocate for leadership development within underrepresented communities in the technology

sector. She is currently the Executive Champion for the Latin and Hispanic Community at Red Hat, and previously the Executive Sponsor for the LGBTQ+ Community at Red Hat. Carolyn is also the Executive Sponsor of Red Hat's Sustainability Program. Before her tenure at Red Hat, Carolyn held significant financial and operational roles at Cisco Systems and Hewlett Packard.

Carolyn is also the co-founder and Chief Financial Officer of the Elizabeth Nash Foundation, an organization dedicated to improving the lives of individuals living with CF. Carolyn is the wife of the late Patrick Nash, and the proud mother of adult twins. She is also the sister-in-law of the late Elizabeth Nash.



Christine Nash, MBASteering 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.

In 2003 Christine, her parents, and her brother (Patrick) and sister-in-law (Carolyn) 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 through its scholarship program and CF research grants.



Anna Payne Steering Committee

Anna Payne is a 36 year old CF and colon cancer patient living in Middletown Township Bucks County, where she is a dedicated public servant and patient advocate. She works as an administrative assistant for Bucks County Commissioner Diane Marseglia. She is also an elected official serving as the Chair of board of Supervisors in Middletown Township. She serves as Vice Chair on the PA rare disease advisory council. She recently started a non-profit known as the Bucks County CF Alliance with a mission to help CF stand for "cure found"

and raise awareness about the link between CF and colon cancer.



Joseph Pilewski, MD *Faculty*

Dr. Joseph M. Pilewski is Professor of Medicine, and Associate Professor of Pediatrics and Clinical and Translational Science at the University of Pittsburgh. He is Associate Chief for Clinical Affairs in the Pulmonary, Allergy, Critical Care, and Sleep Medicine Division at the University of Pittsburgh Medical Center (UPMC) and was Medical Director of the Lung Transplant Program from 2004 to 2015 and 2021 to 2022. He is co-director of the Cystic Fibrosis Program. He is a CF and lung transplant physician and has contributed to basic and clinical

investigations related to CF and lung transplantation. His basic science studies focused on human airway epithelial ion transport. His clinical investigations have focused on new therapies for CF, as he has been director of a CF Translational Studies Core and the principal or associate investigator on over 20 investigator-initiated and multi-center clinical trials in CF. He is an active contributor to the CF Therapeutics Development Network and currently serves as Chair of the Clinical Research Executive Committee. As co-Executive Director of the CF Lung Transplant Initiative, he is contributing to research efforts to improve the care of individuals with CF before and after lung transplantation.



Deepika Polineni, MD, MPH *Faculty*

Deepika Polineni completed her residency in Internal Medicine and fellowship in Pulmonary Medicine with an emphasis on cystic fibrosis (CF) care and translational research. She joined Washington University in St. Louis in 2022, where she serves as the Cystic Fibrosis Center Director and is an Associate Professor in the Department of Pediatrics, Division of Allergy and Pulmonary Medicine. Her research program focuses on the identification of non-CFTR genetic modifiers of CF lung disease using human airway transcriptomics and metabolom-

ics to identify novel gene targets, and airway cellular models to study mechanisms of influence. These 'omics translational studies are complementary to the efforts of the International CF Modifiers Consortium with the goal of advancing personalized therapies in CF.

Dr. Polineni has served as a lead principal investigator in international clinical trials of CFTR modulators and supported a diverse body of CF research as a site-level clinical trial investigator. She serves on the Medical Advisory Committee and the Research Advisory Committee for the Cystic Fibrosis Research Institute. She additionally co-chairs the Preclinical/Clinical working group of the Cystic Fibrosis Foundation Genetic Therapies Working Group. These efforts are aimed at supporting care for people with CF and advancing new therapies, particularly mutation agnostic nucleic acid-based treatments, with the goal of reducing health disparity gaps and serving a global CF community.



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 (CF) 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 CF 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.



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), where she serves as the Medical Director of Clinical Research Services, 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. She has published more than 140 manuscripts as well as a book and multiple book chapters. Additionally, she serves on a number of 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.

Dr. Taylor-Cousar is a staunch advocate for racial justice both in academic medicine and for people with CF. She was one of the founding members of the NJH Diversity, Equity and Inclusion (DEI) council (2015) and served for two years as the NJH interim Associate Vice President of DEI. Beyond NJH, she is a member of the CFF's Racial Justice Working Group, Co-Chair of the of the CFF Health Equity Team Science Award study section, a member of the ATS Workshop on Research Priorities in Pediatric Asthma: Addressing Systemic Racism, and an external advisory member for the NIH P3o Georgia CF Core Center focus on Achieving Health Equity in CF Care and Research. She has also partnered with several CF patient organizations to increase awareness of the occurrence of CF in people of color.

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 Institute CF Champion Award (2021).



Ahmet Uluer, DO, MPHFaculty & Steering Committee

Ahmet Uluer, DO, MPH, is the Director of the Adult Cystic Fibrosis Program, Adult Therapeutic Development Center and Co-Center Director of the combined Boston Children's Hospital and Brigham & Women's Hospital CF Center. He is also the Chair of the Protocol Review Committee of the TDN and separate from his CF work, he directs the BRIDGES Adult Transition Program at Boston Children's Hospital, providing age-appropriate care and transitional care support to adult survivors of pediatric acquired chronic illness. In addition

to his interest in global health, helping improving CF care outside the US, Dr. Uluer has also been interested in researching complications associated with aging, including kidney injury and hearing loss. He received his undergraduate degree from the University of Michigan, medical degree from Kansas

City University of Medicine and Biosciences, Med-Peds residency at the Cleveland Clinic where he was chief, and trained in pulmonary medicine at Boston Children's Hospital and informally at Brigham and Women's Hospital. He earned a MS from SUNY at Buffalo and more recently graduated with an MPH from the Harvard TH Chan School of Public Health.



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-elect

of the American Thoracic Society's Public Advisory Roundtable, and a member of the ATS Early Career Professional 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. A San Francisco Bay Area native, Siri lives in Santa Cruz, California.



James R. Yankaskas, MDFaculty & 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



Bret Ambrose

I am 63 years old and just passed 10 years post double lung transplant on September 23rd of this year. I grew up in rural Northwestern Pennsylvania and was diagnosed with cystic fibrosis in the mid 1960s at Children's Hospital in Pittsburgh, PA. As a graduate of Penn State University I was employed in Technical Electronics Sales for Military and Aerospace as well as High End Medical Equipment applications. I am married to my wife Brenda for the past 35 years and reside in the Kansas City area with our Golden Doodles Bodee and Josey. I am an avid sports fan (having participated in youth and high school wrestling,

baseball, football and tennis). I also grew up hunting, fishing, and boating and continue those activities plus golfing today. On a whim, I picked up the guitar during the COVID pandemic.



Crystal Boeckel

Crystal is a 32-year-old mother of two who recently celebrated her seventh 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 home- schooling 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 Con-

ferences, 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.

CF Adult Speakers



Ed Canda, MA, MSW, PhD

Edward R. Canda, MA, MSW, PhD, is Professor Emeritus in the School of Social Welfare at the University of Kansas. His work addresses connections between cultural diversity, spirituality, and transformational growth through health and mental health challenges. In 2013, Dr. Canda received the Council on Social Work Education's Significant Lifetime Achievement Award for innovations on spirituality through scholarship and education. He combines experiences as a senior living with CF and as a social work scholar to advocate for holistic and strengths-based approaches to CF research and services.



Joshua Hillman, JD

Josh, 29, is the youngest of three. He and his brother Dominic, 34, were diagnosed with a rare CF mutation at birth. Born in Mississippi, Josh spent most of his life in Alabama before moving after college to Boston and then Washington, D.C., where he currently lives. He is a graduate of the University of Alabama and Harvard Law School, and he currently serves as a Counsel to Senator Sheldon Whitehouse on the United States Senate Committee on the Judiciary.



Maureen Kahr

Maureen Kahr is a 55-year-old living with cystic fibrosis (CF), and thriving despite the challenges that go along with having CF. She lives with her husband in Northern Virginia, and loves walking her dog, relaxing on a beach, reading a good book, and hiking in Shenandoah National Park. Professionally, she has 30 years of experience working as an economist in the federal government, but her personal relationships as a friend, daughter, sister, wife, and mother are what bring her the most happiness. Maureen enjoys giving back to her community, including the cystic fibrosis community. She volunteers her time

distributing food to the needy through Food for Others in Fairfax, Virginia, as well as collecting food through her church. She also volunteers as a member of the Inova Hospital Cystic Fibrosis Patient and Family Advisory Board, and was a speaker at NACFC in 2023 on a session about Care Model Compliance. Maureen actively participates in many cystic fibrosis related activities such as, Cystic Fibrosis Cycle for Life, BreatheCon, RoseUp, CFYogi, and CFRI's CF Wellness classes.



Alexandra Rosado

Alexandra "Lexxy" Rosado is a 42-year-old living with cystic fibrosis. Lexxy was diagnosed with cystic fibrosis when she was one year old. She was born in Puerto Rico and moved to Boston at the age of 6.

CF Adult Speakers



Emily Schaller

Emily Schaller, 42, is a heroine with one goal in mind, to Rock CF. Equal parts spark, wit and humor, Emily is claiming her victories against cystic fibrosis having launched the Rock CF Foundation in 2007 to heighten public awareness and raise funds to increase the quality of life for everyone with CF. Emily created and manages an internationally acclaimed line of merchandise to help fulfill the mission of Rock CF. Today, Emily's battle against this deadly genetic disease is printed in Runner's World, FORBES, The Atlantic and SPIN magazines, the New York Times, The Washington Post, USA Today, NPR and posted

on Competitor.com, Shape.com, the Associated Press, and various cystic fibrosis focused educational websites. She is a marathon runner, super teacher and speaker, addressing parents, patients and audiences about the effects of cystic fibrosis and the ever-changing and improving treatments being made. Through Emily's humor and personal experience, she inspires the masses to transform their lives with exercise, diet and goal setting.



Abhijit Tirumala

Abhijit "Abhi" Tirumala is a 22-year-old CF patient with a nonsense mutation living in the Bay Area. He graduated from Santa Clara University last spring with a B.S. in Neuroscience, and just finished his year-long service term with National Health Corps San Francisco. He is interested in and passionate about biomedical science and wants to become a physician in the future. He was diagnosed at the age of three, and he has an older brother who was also diagnosed at the age of five. From his personal experience, he has not met many South Asian individuals that have cystic fibrosis. Therefore, he hopes to be

able to help increase South Asian representation and awareness within the cystic fibrosis community, and to advocate for the importance of diversity in clinical trials.



Max Winkler

Max Winkler was diagnosed with cystic fibrosis (CF) at five weeks old via a sweat test in the spring of 1986. A native of Colorado, he resides in Denver with his wife, Kristen, and their son, Theo. Max is currently the Strategic Unit Supervisor at the Colorado Department of Health Care Policy and Financing (Colorado's Medicaid Department), where he oversees communication and stakeholder engagement strategies, strategic planning, data evaluation, and technical strategy support for the department's older adult and disability services division. In addition to his public service role, Max owns a database con-

sulting company that assists non-profits and universities across the country. He previously spent a decade in the field of brain injury, designing services and supports for survivors throughout Colorado. Outside of work, Max is an avid golfer and a passionate foodie, always in search of the next tee time or culinary project.



Ali Al Safi, MD (MBchB)

I'm Ali Al Safi, a 2nd-year Infectious Diseases fellow at the Ohio State University, focusing on Transplant and Oncology Infectious Diseases. I was born and raised in Baghdad, Iraq, and completed my internal medicine training at Nuvance Health in New York, where I served as a 3rd-year chief resident. I'm passionate about medical education and health equity, having led initiatives on diversity, equity, and inclusion, and I enjoy mentoring students and residents. My clinical interests include phage therapy, infections in cystic fibrosis patients, and infections in immunocompromised hosts. Outside of work, I love

playing and watching soccer, photography, and trying new restaurants.

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Sally Askar, MD, MPH

Sally Askar is a third-year pulmonary & critical care medicine fellow at the University of Michigan. She was drawn to cystic fibrosis after working with incredible CF mentors, patients, and care team early on in her fellowship. She has an interest in clinical research, particularly studying asthma and biologic therapy within CF. She is really excited to be a part of the inaugural CFRI Patrick Nash Fellows Training Program and looks forward to meeting other fellows and the panel of world-leading CF experts. In her free time, Sally enjoys spending time with her family and friends, reading, traveling, trying new cuisines and cafes,

and singing at her church choir.

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Crystal Cobb, DO

Crystal is an endocrinologist at Emory University School of Medicine where she practices as a faculty endocrine hospitalist and outpatient at Emory's adult cystic fibrosis clinic. Her research interests include studying endocrine outcomes in cystic fibrosis during healthcare transition from pediatric to adult care and cystic fibrosis endocrinopathies in the emerging adult population. Crystal completed her undergraduate medical education at Campbell University School of Osteopathic Medicine, internal medicine-pediatrics for residency at UMass Chan - Baystate Medical Center where she served as chief resident

during her final year and recently finished her endocrinology fellowship at Emory University. In her free time she enjoys traveling, trip planning, thrifting and undertaking adventures with friends and family back home in New England.

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Ted Cybulski, MD, PhD

Ted Cybulski is an Adult Pulmonary and Critical Care fellow at Northwestern University Feinberg School of Medicine. He completed his MD and PhD at Northwestern, then continued with a combined residency and fellowship as part of the Northwestern Physician Scientist Training Program. He has a background in biological engineering and machine learning and investigates transcriptomic changes to the nasal epithelium in CF under the mentorship of Drs. Manu Jain and Alexander Misharin. Ted is working toward a career as a physician scientist with a clinical interest in CF care and non-CF bronchiectasis.

His career research interests include integration of molecular data with clinical informatics to better understand determinants of clinical trajectories for people with CF.

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Alex Despotes, MD

Dr. Alex Despotes is a pediatric pulmonary and adult pulmonary / critical care fellow at the University of North Carolina at Chapel Hill (UNC). She completed her medical degree and Med Peds residency at UNC, and subsequently served as the Med Peds chief resident. Her clinical and research interests include cystic fibrosis (CF), primary ciliary dyskinesia (PCD), and non-CF bronchiectasis. Her current investigator-initiated research focuses on aging in CF, understanding the workforce challenges caring for the CF population as it is changing, and clinical trials incorporating the non-CF bronchiectasis population.

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Veronica Grosse-Cardinale, PsyD

Veronica Grosse-Cardinale, PsyD, graduated with her doctorate in clinical psychology from Nova Southeastern University (NSU), with specialized training in clinical health psychology. She completed her residency as the Co-Chief Intern at Broward Health Medical Center, and her post-doctoral fellowship at Jackson Memorial Hospital/the University of Miami Miller School of Medicine in the consultation/liaison rotation working with medically compromised populations, including oncology and lung transplant intensive care. Her research has focused on interdisciplinary public health needs of marginalized communities,

and her clinical work focuses on the psychological well-being in those living with chronic and terminal illness. Throughout her training, she became a tobacco treatment specialist, was a Florida Area Health Education Center Scholar through NSU's College of Osteopathic Medicine, and has been involved in multiple interdisciplinary teaching and training roles to medical students and nursing staff. She was also a recipient of the 2024 Postdoctoral Health Psychology Award for Clinical Excellence through the American Psychological Association's Society for Health Psychology.

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Chelsea Lau, MD

Chelsea Lau is a second year Hematology/Oncology fellow at Northwestern's Robert H. Lurie Comprehensive Cancer Center. She completed her medical school and residency, including chief residency, and the University of Virginia Medical Center prior to joining the Hematology/Oncology program at Northwestern where she participated in quality improvement in multidisciplinary care of cystic fibrosis under the mentorship of Dr. Dana Albon. She is currently a trainee under the Northwestern University Translational Research in Hematology and Oncology NIH T32 training grant, and her primary research involves

investigating the impact of underlying conditions on risks of immunotoxicity in thoracic, genitourinary, and cutaneous malignancies. She plans to pursue a career as an academic oncologist and clinical investigator after completion of her fellowship training.

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Sharon Li, MD

I am a native Texan and internal medicine-pediatrics trained provider, currently in my clinical fellowship at the University of Minnesota in the fields of adult pulmonary and critical care medicine. One of my goals during fellowship and beyond is to study models of care across the lifespan, particularly for people with complex and lifelong medical needs such as those with cystic fibrosis. Of specific interest to me is addressing vulnerabilities during transitions of care, especially the transition between the pediatric care model and adult medicine. In my time away from medicine, I love to spend time with my dog, read the lat-

est in lighthearted fiction (lately, it's been: Emily Henry, Carley Fortune, Sarah Adler, Richard Osman), and go to early morning yoga sculpt for exercise dance parties before my workday.

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Monique Maher, MD

I was born in California attending undergraduate and medical school at UCLA. I then completed internal medicine/pediatrics residency at Baylor College of Medicine in Houston, TX. I am currently a PGY7 and in my 3rd year of a combined IM/Ped endocrinology fellowship at University of Colorado. My career interests include treating CF-related endocrinopathies and focusing on improving transitions from pediatric to adult endocrine care.

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Evan Manning, MD

Dr. Evan Manning is in his final year of training as a cardiovascular disease fellow at the University of Minnesota. Dr Manning is completing a specialty fellowship in preventive cardiology with research focused on the impacts of chronic inflammation on the development and progression of cardiovascular diseases. His clinical interests include exploring unique cardiovascular risk profiles of patient populations not captured in large clinical trials.

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Jessa Miller, MD

Jessa Miller, MD, completed her residency in Otolaryngology - Head and Neck Surgery at the University of California, Los Angeles, and is currently a Rhinology and Skull Base Surgery fellow at UCLA. She double majored in Neuroscience and Biomolecular Science at the University of Michigan for her undergraduate training, and then attended the University of Michigan Medical School for her medical degree. Dr. Miller's research interests include CF and inflammatory sinus disease. After completing her fellowship, she plans to continue doing clinical research and treating complex sinus and skull base pathologies.

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Joseph Moo-Young, MD

Joseph is a second-year adult pulmonary and critical care medicine fellow at Brigham and Women's Hospital in Boston, MA. Prior to fellowship, he completed an internal medicine and pediatrics residency at Vanderbilt University Medical Center in Nashville, TN. He is interested in transitions of care for patients with CF and other congenital lung diseases, and health services research.

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Cory Martin Powers, MD

I'm from Indiana and got my Biochemistry degree from Purdue University. I went to medical school at Indiana University in Indianapolis, where I also did my residency in internal medicine and pediatrics. Currently, I'm in my third year of pulmonary-critical care fellowship at IU. My clinical and research interests are cystic fibrosis and high-risk asthma, especially concerning the transition of care for patients.

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Prachi Saluja, MD

Originally from India, I completed medical school in Delhi before relocating to the United States for residency. Currently, I am pursuing a fellowship in Pulmonary and Critical Care Medicine at the University of Cincinnati. With a strong interest in cystic fibrosis, I began exploring the impact of Trikafta on pregnant women during residency, which ignited a passion for advancing research in this field. Outside of medicine, I am an avid traveler, food enthusiast, and coffee lover. My recent adventure took me to the Dominican Republic, where I soaked up the sun and enjoyed the beauty of the sea. With aspirations

to deepen my knowledge and contribute meaningfully to cystic fibrosis research, I am dedicated to making a difference in the lives of patients and their families.

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Sandy Sufian, PhD, MPH

Sandy Sufian is a Full Professor in the University Illinois-Chicago's Department of Medical Education, the Department of Disability and Human Development, and the Department of History. Sandy got her PhD from New York University and her MPH at Oregon Health Sciences University. She was a postdoc in Health Services Research at the Center for Health Research of Kaiser Permanente in the Northwest. Sandy is a historian of medicine and disability by training. For the past six years, she has also been conducting research and patient-centered outcomes projects with grants from PCORI and the Cystic

Fibrosis Foundation on sexual and reproductive health (SRH) issues for women with Cystic Fibrosis. Dr. Sufian co-founded the Cystic Fibrosis Reproductive and Sexual Health Collaborative (CFReSHC), a partnership with the CF female community to identify research priorities and questions about SRH and CF. She was PI on a project to create a sexual and reproductive health guide by patients for providers and patients (cfreshc.org/srh-guide). She was the Co-PI for a recent MENSTRUAL study that examined CF symptoms across the menstrual cycle. She was also the PI for a PCORI Engagement Award that applied the CFReSHC framework for devising patient-driven research questions in the breast cancer community. She has presented several posters and talks at NACFC and other conferences. She was also a NAPCRG and Menopause Society fellow. She has published three books, numerous articles, and several op-eds on disability issues. She teaches medical and PhD students about the intersection of health, disability, and disease in society.

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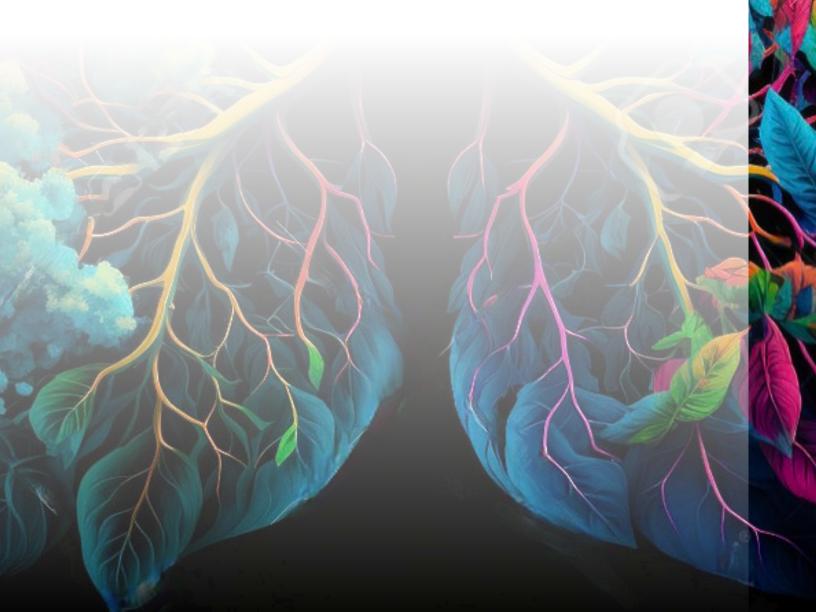


Spyridon Zouridis, MD

My name is Spyros, and I was born and raised in Greece, where I completed my medical education at the National and Kapodistrian University of Athens Medical School. In 2020, I moved to the United States for my Internal Medicine residency, and in 2024, after a year of clinical research training, I began my Gastroenterology fellowship at Saint Louis University, a Cystic Fibrosis (CF) accredited center. During my research year, I had the opportunity to collaborate closely with CF experts, which led me to uncover numerous underexplored areas within the field of cystic fibrosis. My current research focuses on hepatic

steatosis in adults with CF. Specifically, I aim to describe its prevalence and investigate factors that may contribute to its development. Ultimately, my goal is to understand the mechanisms driving the disease and identify those adults with CF at risk for progression to advanced liver disease.

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Epidemiology and the Changing Demographic and Challenges

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 highlight the perspectives of two adults living with CF on aging with CF and implications for their health. The epidemiology of the CF population and common CF-related complications that increase in prevalence with age will be reviewed. A few key general health issues of aging will be highlighted with a discussion of how these issues may differ in people with CF and how they are captured in CF Foundation Patient Registry. Lastly, there will be a brief discussion on the opportunities for greater partnership with primary care physicians and other specialists to ensure high quality, coordinated care for the aging CF population.

Increased Risk of GI and Other Cancers in People with CF

Steven D 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.

A number of 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 that 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?

Lung Transplant for Cystic Fibrosis

Joseph Pilewski, MD

Lung transplantation provides a treatment option for many individuals with advanced lung disease due to cystic fibrosis (CF). Survival has improved over time and the opportunity for transplant has expanded to include individuals who previously were not considered candidates for transplant. Criteria

to be a transplant candidate vary significantly among transplant programs, highlighting that engagement of more than one transplant program may be necessary. Individuals with highly resistant CF pathogens, malnutrition, osteoporosis, CF liver disease and other co-morbidities may be suitable candidates for lung transplant, or if needed, multi-organ transplant. The transplant process involves several phases, from discussion of prognosis and referral to a transplant center, to transplant evaluation, to listing, transplant surgery, and care after transplant. Survival after transplant for CF is improving, to a median survival of approximately 10 years, and most transplant survivors enjoy significant improvement in quality of life. While the availability of highly effective CF transmembrane conductance regulator (CFTR) modulators for many individuals with CF has improved lung function and slowed progression to respiratory failure, early discussion regarding transplant as a treatment option and referral to a transplant program are critical to maximizing opportunity and optimizing patient and family experience. The decision to be evaluated for transplant and to list for transplant are distinct, and early referral may provide a treatment option that can be urgently executed if needed.

Endocrine Complications in the Aging CF Population

Melissa Putman, MD

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. 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 a significant complication for individuals with chronic conditions, including those aging with cystic fibrosis (CF). As life expectancy for people with CF continues to increase, identifying, preventing, or modifying CVD risk factors leading to atherosclerosis, pulmonary hypertension, and/or heart failure demand our attention. The progression of atherosclerosis may be

accelerated in CF patients due to chronic systemic inflammation and disease-specific factors, including cystic fibrosis-related diabetes (CFRD), hypertension, and dyslipidemia, among others. These factors, combined with increased oxidative stress, can promote early vascular damage. Recent advancements in CF treatment, particularly with CFTR modulators, have markedly improved pulmonary function and overall quality of life. However, while these therapies target respiratory health, they may not directly mitigate CVD risk, necessitating attention to cardiovascular health and monitoring. Primary prevention during critical periods, especially in adolescence and early adulthood, offers an opportunity to address modifiable risk factors and delay the onset of atherosclerosis. In addition to regular screening for hypertension, CFRD, dyslipidemia, and other CVD risk factors, it is important to integrate early intervention and appropriately aggressive management into the comprehensive care aging people with CF are accustomed to by their CF care centers. CF care teams have successfully reduced the impact of pulmonary and nutritional complications through preventative approaches. Similarly, addressing cardiovascular health could further extend life expectancy and enhance quality of life in this population.

Modulator Benefits, Complications and Implications on Aging

Deepika Polineni, MD, MPH

Aging with cystic fibrosis (CF) is now becoming an expected norm in the United States. Previous epidemiologic demonstration of a steadily improving survival in CF has been further impacted by the widespread use, and increasingly earlier initiation, of CFTR modulator therapies. CF is a multi-organ disease with well-characterized heterogenous end-organ disease impacts. With CFTR modulator treatment occurring in the majority of people with CF in the US, the diverse nature of CFTR correction and potentiation in adults aging with CF is now becoming increasingly understood. This session will review CFTR modulator benefits, complications, and implications on aging with CF, including special insights toward positive coping strategies toward aging. Dr. Polineni will first review benefits and complications of CFTR modulator therapies in the context of health impacts and a focus on anticipated aging in CF. Dr. Ed Canda will next discuss several of the complex implications of living with an improved expected survival in CF. The session will include the discussion of positive strategies toward aging with CF including coping skills, health and disease self-management, stress reduction and promoting resilience. After completing this session, learners should be familiarized with: multi-organ health impacts of CFTR modulator therapy with an emphasis on benefits and complications related to older age, salient areas of study that remain unaddressed, and critically important perspectives on positive aging with CF.

Career Development & Mentors

James Yankaskas, MD

Mentors can help postdoctoral fellows to plan and achieve their goals by providing advice and assistance on both specific projects and broader career counseling. In this session, an overview will be provided outlining the role mentors can play in supporting the career path of postdoctoral fellows. This will include:

- Academic components & milestones
- · Adult CF care: A valuable component
- · Care, research, leadership options

- Transition opportunities
- · Decisions & mentors
- · Take-home issues

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.

Some Immunological Aspects of CF in the Aging Patient

Richard B Moss, MD

As the immunology of CF is a vast and complex field, our Nash Fellows Conference conversation addressing this issue will necessarily focus on two limited but important aspects: the immunoinflammatory lung complication of allergic bronchopulmonary mycosis (ABPM), an age- and atopy-related progressive but highly treatable condition affecting 10-15% of older people with CF (PwCF); and the susceptibility of PwCF to respiratory infection with viral or bacterial pathogens largely preventable by timely and appropriate vaccination. For the former topic of ABPM (>90% due to A. fumigatus, hence the nomenclature ABPA) I will review key take aways from 2024 guidelines issued by the International Society of Human and Animal Mycology (ISHAM) Working Group on ABPA, published in the European Respiratory Journal and updating prior guidelines from 2013. For the latter topic I will review current immunization recommendations for vulnerable adults (which of course includes even HEMT-treated PwCF) to lower respiratory tract infection with influenza, RSV, SARS-CoV2 and *S. pneumoniae*.

About CFRI

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 CF community.

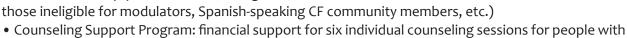
Education

- Annual National CF Education Conference: July 25 27, 2025 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: CFRI Community newsletter twice per year; and Spanish-language CFRI Comunidad once per year
- 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,

CF and their family members



- Community Retreats: a virtual CF Spring Retreat and hybrid Summer Retreat for adults with CF; and an in-person Spring Retreat and virtual Fall Retreat for mothers of children/adults with CF
- Online Mindfulness Meditation Sessions 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

- Nadia Ameen, MD Yale University School of Medicine
- Benjamin Chan, PhD Yale University School of Medicine
- Daria Van Tyne, PhD University of Pittsburgh
- Katrine Whiteson, PhD University of California Irvine
- Feng Yuan, PhD University of Iowa

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

- Steven Jonas, MD, PhD; Ruby Sims, PhD University of California Los Angeles
- Ron Kopito, PhD; Celeste Riepe, PhD Stanford University
- Matthew Porteus, MD, PhD; Anais Amaya Colina, PhD Stanford University

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.