

EVENT RESOURCES



RESEARCHCON



GENERAL RESOURCES

Academic Research Highlights	Provides a snapshot of important academic research studies funded by the CF Foundation. These studies highlight the breadth of research supported by the Foundation beyond just drug development.
Spanish YouTube Playlist: "Fundacion de Fibrosis Quistica (CFF) En Espanol"	This playlist includes a wide variety of educational content, including the "Intro to CF" video series and recordings from virtual events like ResearchCon. This playlist will continue to be updated as new videos become available.
Wellness Opportunities	The CF Foundation is dedicated to helping people with CF thrive in their everyday lives – whether navigating financial challenges, building community and social supports, sharing experiences, contributing to research and science, or finding purpose through creativity and exercise. Preview a list of Wellness Opportunities available to you through the CF Foundation.

SESSION RESOURCES

Opening Keynote: Mental Health Has Entered the Chat	<ul style="list-style-type: none"> • Research 2023 Opening Keynote Presentation • CF and Mental Health: A guide to thriving with ADHD • Managing CF Mental Health • How to Report an Adverse Event
CF Genes: Building blocks for you and your family	<ul style="list-style-type: none"> • ResearchCon 2023 CF Genes Presentation • What is a mutation? • Newborn Screening for CF • History of Newborn Screening • Benefits, risks, and recommendations for state newborn screening programs • CFTR Related Metabolic Syndrome (CRMS) • Clinical guidelines for making a CF diagnosis • After 50 Years, Newborn Screening Continues to Yield Public Health Gains • Recommended Uniform Screening Panel (RUSP) • A retrospective Cystic Fibrosis Foundation patient registry cohort study • Clinical and Functional Translation of CFTR • Guidelines for diagnosis of CF in newborns through older adults: CFF Consensus report • Practice variation of genetic counselor engagement in the cystic fibrosis newborn screen-positive diagnostic resolution process • Pediatric and adult recommendations vary for sibling testing in CF • Screening and Treating Depression and Anxiety Guidelines • Find a Genetic Counselor

<p>Now You Tell Me: Navigating care throughout the lung transplant journey</p>	<ul style="list-style-type: none"> • ResearchCon 2023 Now You Tell Me Presentation • Models of post-transplant care for individuals with CF • Find a lung transplant center • Lung Transplant Referral Guidelines Cystic Fibrosis Foundation (cff.org) • Lung transplant referral for individuals with cystic fibrosis: Cystic Fibrosis Foundation consensus guidelines - Journal of Cystic Fibrosis (cysticfibrosisjournal.com) • OPTN Policy Notice Lung Continuous Distribution Jan 2023 PC (hrsa.gov) • Learn about lung CAS - OPTN (hrsa.gov) • CF Foundation Launches Lung Transplant Biorepository and Patient Registry Cystic Fibrosis Foundation • Patient Registry Cystic Fibrosis Foundation (cff.org)
<p>One Size Doesn't Fit All: CF nutrition in a new era</p>	<ul style="list-style-type: none"> • ResearchCon 2023 One Size Doesn't Fit All Presentation
<p>Genetic Therapies: the latest innovations and potential benefits</p>	<ul style="list-style-type: none"> • ResearchCon 2023 Genetic Therapies Presentation • Genetic Therapies for CF: Glossary of Terms • Questions to ask before enrolling in a clinical trial • Understanding Genetic Therapies • Video: Emerging Genetic-Based Therapies for CF • Video: Delivery Challenges Animation • Video: How Genetic-Based Therapies Could Restore CFTR Protein • Patient Safety Is a Priority • Types of CFTR Mutations • Know Your CFTR Mutations • CF Genetics: The Basics • Exploring Treatments for Nonsense and Rare Mutations • Research Into Genetic Therapies • mRNA Therapy • Gene Therapy • Gene Editing • Gene Delivery
<p>Evolving Landscapes and New Horizons in CFRD Management</p>	<ul style="list-style-type: none"> • ResearchCon 2023 CFRD Management Presentation • Cystic Fibrosis-Related Diabetes Overview • Clinical Care Guidelines for Cystic Fibrosis-Related Diabetes • Guide for patients and families on managing CFRD • ISPAD Clinical Practice Consensus Guidelines 2022: Management of cystic fibrosis-related diabetes in children and adolescents
<p>Healthy Sleep and Movement for Every Body in a Changing CF World</p>	<ul style="list-style-type: none"> • ResearchCon 2023 Healthy Sleep and Movement Presentation • Sleep health information and tools • Stay up to date on the latest education around sleep • CF Yogi: A virtual yoga studio with weekly livestreamed yoga classes led by instructors who have firsthand knowledge of yoga and CF. • Coach-Ed: This program provides financial sponsorships for people with CF to participate in fitness-related activities and guidance to find the right sport. • Move Your Way: Tools, videos, and fact sheets with tips that make it easier to get a little more active.

	<ul style="list-style-type: none"> • The Cystic Fibrosis Lifestyle Foundation (CFLF) empowers and educates people with CF toward lifestyle choices that positively impact mental and physical well-being.
What's Bugging You: Updates on Managing CF Lung Infections and Addressing Antibiotic Resistance	<ul style="list-style-type: none"> • ResearchCon 2023 What's Bugging You Presentation • Infection Research Handouts
Closing Keynote: Knocking on the Aging Door: What we know, what we don't know, and where we're going	<ul style="list-style-type: none"> • ResearchCon 2023 Closing Keynote Presentation • Is It My Age or Is It CF 2022 ResearchCon Recording • Clinical Care Guidelines • Bone Disease in CF Clinical Care Guidelines • Get Involved at the CF Foundation • National Institute on Aging (NIA) • National Council on Aging (NCOA) • AARP • Alzheimer's Disease and Healthy Aging Resources • The Cystic Fibrosis Reproductive and Sexual Health Collaborative • Diagnosed with CF as an Adult CF Foundation

CF FOUNDATION SUPPORT SERVICES AND PROGRAMS

Community Conferences	<p>There is something for everyone at a Community Conference. Whether you'd like to meet others going through similar experiences or learn more about CF-related topics, there is an event for you to virtually connect, share, and learn together. Community Conferences Save the Date</p> <p>Are you an adult with CF who is interested in shaping BreatheCon 2024? Apply for the Planning Committee.</p> <p>Register for NextBreath – June 13 and 14</p>
Compass	<p>Cystic Fibrosis Foundation Compass is a personalized, one-on-one service that provides people living with cystic fibrosis, their families, and their care teams with a partner in dealing with challenges related to life with CF. Compass One-Pager</p>
CF Peer Connect	<p>CF Peer Connect offers one-to-one peer support for adults with CF and their family members to connect about shared experiences including living with advanced lung disease, considering a lung transplant, or living post-transplant. No matter what you're going through, there is someone who has been through a similar experience and can offer support.</p>
CF Community Blog	<p>The CF Community Blog is all about sharing the experiences, reflections, and perspectives of the cystic fibrosis community: the good days, the bad days, and all the tough and wonderful things in between. If you are interested in sharing your story, fill out the CF Community Blog interest form today!</p>

Impact Grant Program	<p>The Impact Grant program provides grants of up to \$10,000 per year to individuals or organizations for projects that provide meaningful engagement opportunities for the CF community. The best ideas come from personal experience, and no one knows the ins and outs of life with CF like the CF community. This program is a chance to make your vision a reality. Please see our 2022 Community Grant Directory for a list of presently funded projects that are available to the community.</p>
Community Voice	<p>Community Voice is a chance to be heard. People living with cystic fibrosis and their families know CF better than anyone, and Community Voice is an empowering volunteer opportunity for you to share your experiences, perspectives, and knowledge. Members make an impact by bringing their insights and priorities to the forefront of CF research, care, and programs. Join Community Voice Today.</p>
Mutation Analysis Program	<p>The Mutation Analysis Program provides free genetic testing to people with cystic fibrosis to help identify their CF gene mutations.</p>