

# COMMUNITY VOICE

## 2023 YEAR IN REVIEW



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*"COMMUNITY VOICE HAS BEEN A WONDERFUL platform for our team to retrieve helpful feedback and input from the CF community to help us to improve our study and to gain more knowledge from the community's perspective."*

CHRISTINA BALDWIN CHADWICK, MD

# YOUR VOICE, YOUR IMPACT.



Community Voice is entering its 10th year, transforming how those who work to improve research and programs for the CF community partner with and center the perspectives of those living with the disease. In 2023, we saw a continued trend of deepening the involvement and impact of the community and an increased focus on topics previously underserved or where the community's needs are evolving.

Over the past year, progress was made to:

- Amplify the needs and feelings of those who have been unable to benefit from modulators whether by their genotypes, side effects, or transplant status. Their honest feedback about the challenges they face is helping us to improve research and support programs to ensure that no group is left behind.
- Better understand and begin to address factors that impact health outcomes outside of clinical care, like racial inequities and access to food, housing, transportation, and clean air.
- Advance research and care on topic areas that previous feedback highlighted as key areas of need, such as mental health research and sexual and reproductive health.

Community Voice members sharing their perspectives and partnering with us is critical to the mission of the Cystic Fibrosis Foundation. We are thrilled that Community Voice launched in Spanish in 2023, expanding our ability to hear from the Spanish-speaking community.

We are excited to see what lies ahead in 2024. Several impactful projects are on the horizon, spanning topics like genetic therapies, financial wellness, study designs, and the CF Foundation's long term strategic planning efforts.

With gratitude,

**Christina Román**  
**Director, Community Insights and Partnering**

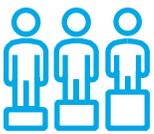
# THE COLLECTIVE POWER OF

# COMMUNITY VOICE

450+ members completed at least one survey, with over  
↳ 2,300+ total survey responses submitted from across the CF community

162 members served on 44 national committees/workgroups  
↳ 24 recruitments that added 82 members in 2023 alone

Community Voice members participated in more than 50 opportunities:



8

projects focused on **health equity**: ensuring all people with CF have a fair and full opportunity to be as healthy as possible.



6

projects focused on **cure**: supporting research to advance new therapies and treatments.



25

projects focused on **care**: supporting the best possible CF treatment and delivery of care to people with CF.



12

projects focused on **community**: expanding the reach of our programs and services to those in need.

# ABOUT COMMUNITY VOICE MEMBERS

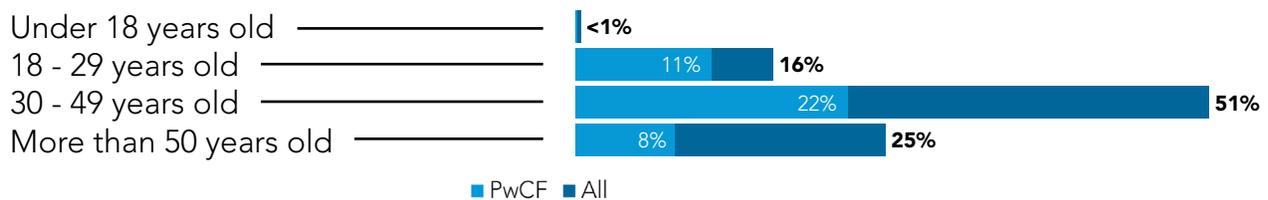


## Connection to Cystic Fibrosis\*

Person with CF:	45%
Parent of a person with CF:	38%
Spouse of a person with CF:	3%
Other: (grandparents, siblings, children, aunts, uncles, in-laws, friends, etc.)	27%

\*Members may have multiple connections to CF.

## Age Range\*

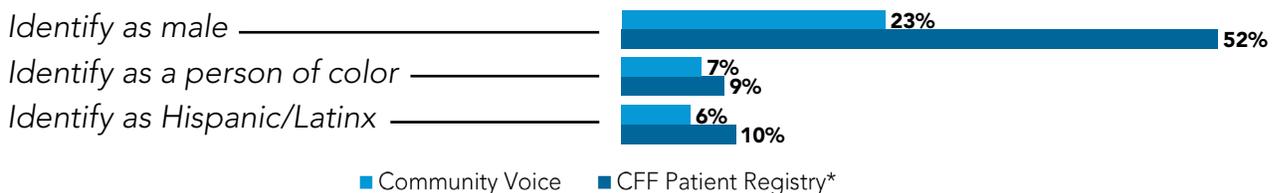


\*8% of members did not disclose their age.

Learn more about the impact members had throughout 2023 in the [Appendix](#) and our [Monthly Results Updates!](#)

## Every voice matters.

Each person's experience is unique, so it is critical to hear from as many people as possible. Groups with underrepresentation in Community Voice that we are working to better engage include those unable to benefit from CFTR modulator therapies, young adults, members of the LGBTQIA+ community and those who:



Members may identify as multiple races/ethnicities.

\*Taken from Cystic Fibrosis Foundation Patient Registry 2022 Annual Data Report.

If you know others who want to get more involved and help shape research, care, and programs, please encourage them to join by visiting [cff.org/CommunityVoice](https://cff.org/CommunityVoice).

## WORKING TOWARDS A CURE FOR ALL

Community input is a vital part of the CF Foundation's relentless pursuit of a cure. In 2023, Community Voice members – including those not eligible for CFTR modulators – made significant contributions to this mission by sharing their perspectives. CF Community insights will continue to be a crucial resource for researchers investigating gene therapies, evaluating treatment outcomes, and designing future clinical trials.

**Continuing to Address Modulator Ineligibility:** The CF Foundation is aggressively pursuing potential treatments for all who do not benefit from CFTR modulators. Community Voice deployed several projects in this space to better understand the perspectives of this community and inform the CF Foundation's efforts to find a cure for all.

*Focus groups to support gene therapy trials:* The Research Expansion to Advance the CF Therapeutic Pipeline for People without Modulators (REACH) study is one of the first of its kind in CF research with its goal being to collect baseline data to be used across many therapeutic trials in order to reduce total number of participants needed and lowering the cumulative research burden on this small population in the CF community. This was an exclusive opportunity for those not eligible for modulators, where community members gave feedback on trial logistics such as travel, home monitoring/reporting, overall study clarity and willingness to participate.

*Interviews with those currently not benefiting from modulators:* The CF Foundation held over 20 interviews with people with CF and parents of children with CF who are not eligible for modulators or who cannot tolerate them due to side effects to better understand their experiences in the CF community, information needs, and to gauge interest and barriers to participating in genetic therapy clinical trials. Initial findings were shared with over 300 clinicians/researchers during the Therapeutics Development Network (TDN) Fall 2023 meeting. To ensure we hear diverse perspectives, a second round of interviews will be conducted in 2024 to hear from more voices.

**Improving and Analyzing Patient Registry Data:** The CF Foundation [Patient Registry](#) collects information on the health status of people with cystic fibrosis who receive their care from a CF Foundation-accredited care center and agree to participate in the Registry. Improved patient registry data will empower researchers to study CF treatments and outcomes more effectively, ultimately driving progress towards improved care and treatments.

*CF Foundation's Patient Registry (CFFPR) Team Study:* This study sought feedback from those who do not benefit from modulators (by genotype, not age). The goals of this study were to better understand those ineligible for CFTR modulators, and help the CFFPR team design appropriate registry analyses to study clinical outcomes in this population that could support future genetic therapy research. Researchers met with the community via focus groups to get their input on the study analysis plan and again to review the study results. Community input helped inform how they presented the data, and results are being submitted in early 2024 for publication in a journal.

# PROJECT SPOTLIGHT

## Clinical Research Executive Committee (CREC) Recruitment:

The **CREC**, which assesses and prioritizes incoming research protocols to the Therapeutic Development Network (TDN), welcomed its first CF community member in 2022. In 2023, a second CF community representative joined the CREC, to help provide perspectives from someone who is not able to benefit from a modulator.

*"INCLUDING THE CF COMMUNITY IS CENTRAL and critical to our clinical research programs. This includes review of research applications and protocols, sanctioning of studies to be conducted in the TDN and development of engagement strategies for those who are new to research. The CF Foundation has incorporated CF community members into all of these steps, including membership on clinical research grant review committees, the Protocol Review Committee and the Clinical Research Executive Committee of the TDN."*

JP CLANCY, CF FOUNDATION STAFF  
(CLINICAL TRIALS)



## HOW SOCIAL AND FINANCIAL FACTORS IMPACT HEALTH

The CF Foundation is emphasizing research related to nonmedical factors – such as social, financial, and environmental influences – that impact people’s health. Also known as **social determinants of health (SDOH)**, these are conditions where people live, learn, work, and play that affect health risk and outcomes. Community Voice supported several projects to better understand these factors in 2023, partnering with the CF community through interviews, committees, and focus groups.

### **Dismantling Barriers Caused by Different Social and Financial Factors**

Community Voice members participated in multiple projects to help identify social and economic barriers people experience and ways to address them to create better health outcomes.

*Interviews on financial challenges associated with CF:* Community Voice members participated in interviews to share their thoughts on clinic discussions about challenges paying for the things needed to manage CF. The findings led to an **abstract** (Abstract 375) presented at the North American Cystic Fibrosis Conference (NACFC). Researchers found that community members are very comfortable talking about financial challenges, and that it can be helpful if clinicians initiate those conversations.

*Committees on social and financial factors:* The CF Foundation established new committees to continually learn from the CF community, as well as CF clinicians, about the many factors that affect CF care. Members of the new Social Determinants of Health (SDOH) Advisory Committee will inform CF Foundation work as it relates to SDOH and CF. The newly-formed Financial Wellness Advisory Committee will help shape further exploration of financial priorities among members of the CF community including how people manage current needs for money, cope with unexpected costs, and plan for the future in order to thrive.

*Cost Burden Research Survey Working Group:* Community Voice members prioritized topics and helped to develop questions for two surveys (one for patients, and one for care teams) on financial stressors and their impact on daily life and equitable access to high quality CF care.

### **Equity in Action: Advancing Racial Justice, Diversity, and Inclusion**

The CF Foundation’s **commitment to equity, racial justice, diversity, and inclusion** is directly linked with the need to address nonmedical factors that affect people’s health outcomes.

*ERJDI Implementation Advisory Group:* Community members of this group provided guidance and insight as part of developing of a plan and concrete steps to put into action the Foundation’s External Racial Justice Working Group (ERJWG) **recommendations**. This group specifically includes members from the Black community that live with or are impacted by CF. Community members part of this group are playing a pivotal role in ensuring that the Foundation’s commitment to helping address the systemic barriers that have led to health disparities for many in the CF community — Black, Hispanic, and other communities of color — is realized.

*Inclusive Data Collection Feedback Survey:* Members who completed this survey are supporting the CF Foundation’s efforts to improve data collection processes regarding demographic information. Participants weighed in on questions about race, ethnicity, gender identity, and preferred pronouns. This survey was open to everyone in the CF community (adults, parents/ caregivers, CF clinicians, and CF researchers).

# PROJECT SPOTLIGHT

## Social Determinants of Health Language Focus Groups:

Community members participated in focus groups to shape how the CF Foundation talks about social determinants of health. Their work will help to ensure the topic is addressed in an understandable and relevant way to the CF community and to develop educational materials for the community and clinicians.

**"I'M IMMENSELY GRATEFUL**

*for all the incredible individuals who participated in the SDOH language focus groups. These individuals were open, vulnerable, and willing to share their ideas and experiences. Their input will help shape the development of educational materials, influence the way we communicate broadly about the topic, and improve our ability to reach more people with resources and services available to support them."*

**CRISTEN CLEMM, CF FOUNDATION STAFF  
(HEALTH SYSTEM NAVIGATION)**



## UNDERSTANDING SEXUAL AND REPRODUCTIVE HEALTH AND CF

As some members of the CF community are living longer and experiencing better health outcomes, the need to explore, prioritize, and understand community experiences with sexual and reproductive health is growing.

### **Highlighting Community Priorities Related to Sexual and Reproductive Health**

Community Voice supported multiple related projects this year, seeking community input on what areas of sexual and reproductive health are most important to them.

*Sexual and Reproductive Health Survey:* The CF Foundation's Therapeutics Development Network (TDN) Sexual Health, Reproduction, and Gender Research (SHARING) work group surveyed community members to collect priority topics for national studies focused on understanding and treating aspects of sexual and reproductive health in men, women, and all genders. This survey was the first prioritization survey under the SHARING work group, and is intended to enhance quality of life and comprehensive care for all people with CF. Survey results were **published** and shared during NACFC (see **59:08**).

*Male Sexual and Reproductive Health Priorities:* Community members participated in an online brainstorming, rating, and sorting activity to identify and prioritize topics related to male sexual and reproductive health and CF. Community input from these activities will be used to prioritize future research and develop new strategies to incorporate male sexual reproductive health topics into routine CF care.

### **Supporting Decision-Making and Conversations about Sexual and Reproductive Health**

Community members shared their perspectives on how to better support conversations related to sexual and reproductive health, their decision-making around becoming a parent or not, and among many other topics.

*Decision-Making Tool for Females with CF:* Community members participated in interviews to review an online decision-making tool about female sexual and reproductive health. While the existing tool is currently targeted at adult women with CF, researchers are using community insights gathered through these interviews to understand the value or usefulness of the tool for adolescents and young adults with CF who were assigned female at birth.

*Reproductive Genetic Counseling for People with CF:* Community members shared their perspectives in interviews regarding reproductive genetic counseling for people with CF. Researchers are gauging community views, experiences, and awareness of prenatal and preconception genetic counseling. Findings from the interviews will be used to develop an online reproductive decision-making tool and improve future clinical experiences for people with CF.

# PROJECT SPOTLIGHT

## CF Sexual and Reproductive Health Guide Updates:

Through the Cystic Fibrosis Reproductive Health Collaborative Chapter Revision Work Group, five Community Voice members provided revisions to eight existing chapters in their CF Sexual and Reproductive Health Resource Guide. The chapters that will be updated with research related to the aforementioned topics include 1) Family Planning, 2) Infertility, 3) Parenthood, 4) Body Image, 5) Hormones, 6) Sexual Function, 7) Pregnancy, and 8) Contraception. CFReSHC is a 2023 recipient of a Community Support Grant from the Cystic Fibrosis Foundation.

### "SEXUAL AND REPRODUCTIVE HEALTH (SRH)

*research and healthcare in CF has always been lacking in my opinion — I was so glad to not only see that this group of extraordinary CF providers and researchers are doing something about it, but to be a part of it and have real influence on moving this field forward. The other members of SHARING and I are treated as equal members of this group, which shows how much the CFF and their associated working groups value contributions and input from the community. It restores my faith in the overall mission of the CFF."*

MADDIE POTRANSKI, COMMUNITY VOICE MEMBER



## NO HEALTH WITHOUT MENTAL HEALTH

As highlighted at the 2023 North American Cystic Fibrosis Conference (NACFC), *there is no health without mental health*. Researchers and clinicians are exploring ways to integrate greater focus on and support for mental health into CF care and research. Community Voice members have expressed strong interest in and willingness to share their experiences with CF and a range of mental health challenges and considerations.

### **Identifying and Addressing Medical Traumatic Stress**

Medical traumatic stress is a set of psychological and physiological responses to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences. It may occur as a response to a single or multiple medical events. Both children and adults can experience medical traumatic stress, which may negatively impact their mental health and cause physical symptoms.

*Medical Traumatic Stress in Children Advisory Committee:* Researchers are seeking to understand if and how the challenges that children with CF and their families are experiencing are related to medical traumatic stress. This advisory committee — which includes three Community Voice members (one adult with CF and two parents of children with CF) — is helping to advise on proposed ways to help address medical traumatic stress in children with CF, with the goal of getting families support sooner and preventing medical trauma.

*Interviews on Medical Traumatic Stress:* Adults with CF and parents of children with CF also advised researchers on a new patient questionnaire about medical traumatic stress and CF. The questionnaire is intended to help with self-reported identification of medical traumatic stress exposure and symptom scale.

### **Supporting Improved Screening for and Research on Mental Health**

Community members weighed in on ways to better identify and treat mental health, including the unique challenges that living with CF can pose.

*Interviews to Support CF Mental Health Screening:* Community members participated in individual interviews about their experiences with CF and mental health to support the development of a new screening tool for people with CF. The screening tool will help clinicians identify common, impactful, and highly treatable mental health conditions other than depression and generalized anxiety in adults with CF.

*Prioritizing Research in Mental Health (PRIME) Working Group:* Community members joined a working group to help improve the understanding, prevention, diagnosis, and treatment of mental health concerns for people with CF. CF community members have presented results from the Mental Health Research Prioritization Survey to researchers and contributed to discussions about research priorities related to CF and mental health. The working group discussed priorities for future research including medical trauma, aging with CF, and long-term effects of modulators on both physiological and psychological health.

# PROJECT SPOTLIGHT

## Mind-Body Interventions for Pain:

Researchers interviewed adults living with CF to better understand their experiences coping with CF-related pain. Community members noted that pain is a part of life with CF, noting that it can impact their quality of life, especially their mental health. Some community members shared that their experiences of pain were not taken seriously, waiting for years to receive treatment, and advised CF teams to listen and validate pain experiences in people living with CF. The results from these interviews are being used to develop a CF-specific non-medication mind-body intervention for pain management and will support a multi-center pilot trial. Researchers expressed that the content and quotes from the interviews used in the materials are helping to destigmatize the topic and let community members know they are not alone in experiencing CF-related pain.

*"COMMUNITY INVOLVEMENT IN CF MENTAL health efforts is invaluable in many ways... Community advisors are essential to our mental health research projects. Community input helps set the agenda for what we need to learn as well as how we design and carry out research. Community members speak with the authority of lived experience, and I've noticed that their voices are often the most persuasive in the room!"*

DR. ANNA GEORGIPOULOS, CHAIR OF PRIME MENTAL HEALTH WORKING GROUP



## COMMUNITY CONNECTIONS

In 2023, Community Voice members – alongside other members of the CF community – continued to build connections and mutually support one another. Many of these events and opportunities are organized by the community for the community, and the Community Voice program is proud to support and share them whenever possible.

Here are just a few of the ways in which the CF community came together in 2023, including contributions made by Community Voice members:

### Shaping and Hosting Community Conferences

Community Voice members joined other members of the broader CF community in planning, hosting, speaking at, and attending virtual community-led conferences, including ResearchCon (CF-related science and care), BreatheCon (for adults with CF), and NextBreath (experiences living with advanced lung disease or lung health complications). Community Voice members helped plan and co-chaired all three conferences in 2023, and are serving as co-chairs for BreatheCon and ResearchCon in 2024. Learn more about upcoming events on the [Community Conferences website](#).

### Supporting Each Other through CF Peer Connect

Some Community Voice members are also members of [CF Peer Connect](#), a one-to-one peer support program for English- and Spanish-speaking people with CF and their family members. In 2023, CF Peer Connect and Community Voice teamed up to recruit participants who are 40 years and older and were diagnosed with CF as adults to serve as potential peer mentors to others diagnosed as adults.

*"I FEEL I HAVE A DIFFERENT*

*point of view based on my age and how I was raised and grew up with CF and was able to live the life I have been living."*

*ARNOLD WITZKE,  
COMMUNITY VOICE MEMBER*

### Connecting on Critical Topics

In 2023, the CF Foundation began hosting peer-led small group discussions on specific topics related to life with CF. These discussions focus on underrepresented groups within the CF community to provide a place of supportive and social connection among peers. Topics have included delayed diagnosis, living without modulators (ineligible or not currently benefitting from modulators), and CF-related diabetes. Community Voice members have actively attended these sessions, and 13 Community Voice members helped to facilitate discussions. Look for more of these opportunities in 2024, and contact the [organizing team](#) with any questions or ideas.

## COMMUNITY CONNECTIONS CONTINUED

### Next Chapter of the CFF Community Blog

The CF Foundation’s blog team partnered with Community Voice to survey past blog authors, current readers, and the broader community about their experiences with the blog and the type of content and authors they would like to hear from. Most of the 121 respondents said that they would like to read about CF Foundation events, CF-related health conditions, relationships, emotional wellness, and modulators on the blog. Other popular potential topics included fitness, research and/or medical advances, nutrition, aging into CF, and living without modulators. Catch up on the [CF Community Blog](#) or share your perspective – new authors are always welcome!

*“AS I GET OLDER, GIVING BACK*

*is more important. Using my past experiences to help others who are also battling is something I would like to help more with, even if it just helps little bit. Seeing those put so much effort to helping all of with CF encourages me to want to help them as well.”*

*SETH GREGORY, COMMUNITY VOICE MEMBER*

### Consulting on the Adult Advisory Committee

In 2023, the [CF Adult Advisory Committee](#) (AAC) welcomed 6 new members from Community Voice. The committee reviewed community submissions for [Impact Grants](#), selected sessions broadly of interest to the CF community to stream live from the North American Cystic Fibrosis Conference (NACFC), and helped convey adult perspectives to promote an inclusive virtual and hybrid experience at events like the Volunteer Leadership Conference.



*From top left: Rae Alder, Art Brace, Will Corcoran, Tanisha Cunningham, Jen Eisenmann, Jennifer Kyle, Giovanni Peralta, Kasey Raffensperger, Luis Ramirez, and Chad Riedy*

## LOOKING AHEAD

The CF community had an incredible impact through Community Voice in 2023, ensuring that research, the future of care, and ongoing programs took into account the lived experiences and preferences of the CF community. We only expect the demand for CF community input to grow in 2024 and beyond, and we are ready to support both researchers and CF Foundation staff seeking that input and community members generous enough to share their time. Here are just some of the ways we anticipate community perspectives driving progress in 2024 through Community Voice and beyond.

### **New Ways of Partnering with the CF Community:**

**CF Foundation listening year.** In preparation for development of the next 5-year strategic plan, the CF Foundation will be conducting widespread community listening in 2024. Foundation staff, including the Community Voice team, are working to identify gaps and areas where the organization needs input from the CF community. Community listening – likely to include focus groups and surveys – will begin in the second half of the year to make sure the next chapter of CF Foundation work is directly informed by community needs and priorities.

**Reaching as many people as possible.** We're exploring new ways of reaching those we have – and have not – connected with in the past. Everyone with CF deserves to be heard, and we're working to create opportunities that are relevant and accessible to as many people as possible. In 2023, we launched Community Voice in Spanish, and will continue to support the development of Spanish-language opportunities. We're also finding new ways to share information, including how to circulate surveys, focus groups, and interview opportunities to people with CF beyond those who are members of Community Voice.

**Improving data collection.** The CF Foundation is making progress on the next generation of the CF Patient Registry to support greater collaboration with and support for research that relies on critical community data. We're also putting into place new ways of asking demographic questions that reflect CF community preferences for how we talk about identity, including race, ethnicity, and gender.

**Celebrating and sharing.** Community Voice is celebrating its 10th year of community input in 2024! As an anniversary gift back to the community, we will be compiling and sharing information on the program's history, significant impacts you've made over time, and how far we've come in a decade.

### **Growing Areas for Community Input:**

- How to improve individual experiences in care settings, including factors that build or erode trust between families and clinicians
- Health insurance, cost burdens, and financial wellness, to better understand the financial impacts of treating and living with CF
- Drug development pipeline, including gene therapies and clinical trials
- Mental health among both people taking and not taking modulators
- Sexual and reproductive health
- Living longer with CF

# APPENDIX

In this appendix, we are excited to share a comprehensive list of all of the projects that Community Voice helped researchers, clinicians, and CF Foundation staff to partner with the CF community on in 2023.

All projects are listed by category – Cure, Care, Community – except for projects related to Health Equity, which often span two or more of these areas. Health equity work seeks to ensure that all people with CF have a fair and full opportunity to be as healthy as possible. It is a growing area of focus for the CF Foundation, as the organization strives to understand and support a wide range of differing personal experiences with CF and associated care and resources.

## Health Equity

### Health Equity Team Science Award (HETSA) Community Reviewers:



*10 Community Voice participants.*  
HETSA is new CF Foundation funding program for clinical research projects that would make important contributions to

improve health equity in the CF population. Community reviewers are responsible for reviewing applications for this funding, drawing on their own lived experiences and observed community-wide experiences to provide patient perspectives, share community research priorities, and identify possible barriers to community participation in studies. In 2023, HETSA community reviewers were selected from past community grant reviewers or those who served on the External Racial Justice Working Group. In Spring 2024, HETSA community reviewers will be recruited broadly through Community Voice.

### Social Determinants of Health (SDOH) Advisory Committee:



*2 Community Voice participants.*  
The newly-established SDOH Advisory Committee shapes and guides the work of the CF Foundation related to social determinants of health, or factors outside of CF clinics that impact the lives of people with CF. Community members provide input based on their real-life experiences to help identify

and break down barriers that people living with CF may face, such as housing or food insecurity. Initial committee work is focusing on outreach and information sharing, with future plans to advise on related strategic priorities and research projects. The committee helped to develop focus groups around the language the Foundation uses to talk about SDOH, and a community member is helping to analyze the focus groups' results. Community members serve a 1.5 year term, with an option to extend an additional year. This committee collaborates with the Financial Wellness Advisory Committee. The experiences that community members are sharing as part of both committees is helping to advance the CF Foundation's commitment to health equity.

### Financial Wellness Advisory Committee:



*6 Community Voice participants.*  
The newly-established Financial Wellness Advisory Committee advises the CF Foundation on how people living with CF currently meet needs for money, absorb unexpected costs, and financially plan for the future in order to thrive. Initial committee work includes prioritizing financial wellness topics related to CF for further exploration, and may later focus on ways to increase awareness of these topics and the creation, review, and dissemination of community-focused...

## Health Equity

### Financial Wellness Advisory Committee Continued:



...materials on financial wellness. Community members serve a 1.5 year term, with an option to extend an additional year.

This committee collaborates with the Social Determinants of Health (SDOH) Advisory Committee. The experiences that community members are sharing as part of both committees is helping to advance the CF Foundation's commitment to health equity.

### Improving Communications about Social Determinants of Health (SDOH):



14 Community Voice participants in 6 focus groups. CF Foundation staff held focus groups with CF community

members to understand how to better communicate with the community about nonmedical factors that impact health (also known as social determinants of health) which are factors outside the CF clinic that impact their health. Participants indicated that they think these factors should be screened for at every visit, and communications about these factors should help people with CF understand they are not alone in their experiences. Results from these conversations will inform communication strategies, particularly as they relate to educational efforts for clinicians, people with CF, and families of people with CF.

### Community Attitudes on Clinic Discussions about the Challenges of Paying for Things Needed to Manage CF:



16 Community Voice participants in individual interviews. CF Foundation staff interviewed community members on their

willingness to have clinic discussions about nonmedical factors that impact health.

People with CF and caregivers discussed access to or difficulty paying for food, utilities, Internet, transportation, childcare, and other issues related to education, employment, the cost of CF care, and transplantation. The results of the interviews showed that both people with CF and clinicians are comfortable having these conversations, but nonjudgmental interactions are essential to their success, and it helps if clinicians initiate the discussion. The findings led to an abstract presented at the North American Cystic Fibrosis Conference (NACFC).

### Developing Surveys on CF Cost Burdens:



4 Community Voice participants.

The CF Foundation will be launching two surveys in 2024 for patients and care teams on financial stressors related to CF, including their impact on daily life and equitable access to high quality CF care. Community members serving in the working group will help prioritize topics and help in the development and finalization of questions for both the patient and clinician surveys.

### Equity, Racial Justice, Diversity and Inclusion (ERJDI) Implementation Advisory Group:



7 Community Voice participants. This advisory group provides guidance and insight on the development

of an implementation roadmap for the CF Foundation's External Racial Justice Working Group (ERJWG) recommendations. Community members serving on the advisory group are adults living with CF, or are parents or caregivers of Project leads recruited adults living with or impacted by CF (e.g., parents, caregivers) in the African American/Black community. The group will play a pivotal...

## Health Equity

### **Equity, Racial Justice, Diversity and Inclusion (ERJDI) Implementation Advisory Group Continued:**

...role in ensuring that the CF Foundation's commitment to helping address the systemic barriers that have led to health disparities for many in the CF community – particularly Black, Hispanic, and other communities of color – is realized.

### **Feedback on Inclusive Data Collection:**



Survey

*68 Community Voice participants.* The CF Foundation disseminated a survey to the CF community to gauge how people prefer to be asked about questions on their race, ethnicity, gender identity, and preferred pronouns. The survey results will shape how the CF Foundation collects demographic information, including (but not limited to) race, ethnicity, gender identity, and preferred pronouns.

## Cure

### **Research Expansion to Advance the CF Therapeutics Pipeline for People without Modulators (REACH):**



Focus Group

*7 Community Voice participants in 2 focus groups.* Researchers held focus groups exclusively with adults with CF who are not eligible for or able to benefit from modulators and parents and caregivers of people with CF to support the development of gene therapy clinical trials that will be feasible and effective for the community. Focus group participants advised on trial logistics (travel, home monitoring and reporting), overall study clarity, and their willingness to participate in clinical trials. Information from REACH will be used as control data across many different trials – the first effort of its kind in the CF research space. This sharing of information will reduce the burden on the small CF population likely to be eligible for or participate in these genetic therapy studies, and enable more clinical trials to progress without needing to repeatedly identify additional control group participants.

### **Experiences of People Not Eligible for or Able to Tolerate Modulators:**



Interviews

*26 Community Voice participants in individual interviews.* CF Foundation staff from Community Voice and Clinical Trials interviewed adults with CF who are not eligible for or able to benefit from modulators and parents of children with CF not eligible for modulators to understand their experiences living without modulators. Interviewees described how not being on a modulator had affected their physical and mental health, including their engagement with the CF community, and characterized the types of information they receive about ongoing research. They shared perspectives on gene therapies, including their areas of interest, consideration, and concern that could drive or impact their willingness to participate in clinical trials. This project is ongoing, with future interview opportunities planned, and will support the development of clinical trials, programs, and support for the entire CF community.

## Cure

### Clinical Research Executive Committee (CREC):



2 Community Voice participants, including 1 new member.

The CREC is responsible for establishing therapeutic priorities for the Therapeutics Development Network (TDN). Alongside researchers, community members provide input on CF Foundation-sanctioned studies, as the CREC makes decisions on which clinical trials will be approved and prioritized within the TDN. A community member position was first added to the CREC in 2022. The CREC specifically added a role for a community member who is not eligible for modulators in 2023. Future opportunities to join the CREC will be shared with Community Voice as they become available.

### Clinical Research Committee (CRC) Community Reviewers:



16 Community Voice participants, including 8 new members. The CRC is responsible for critically

reviewing, critiquing, and rating clinical research grant applications submitted for different CFF funding opportunities. Community reviewers advise on the relevance of the study's topic area to people with CF and evaluate whether participating in the proposed study would be reasonable from a patient's perspective and the importance of the application's study's topic to the CF community. CRC community reviewers are a mixed group of adults with CF and parents of children with CF, spanning a range of ages and CF experiences. CFF provides community feedback to directly to scientific reviewers and incorporates it into the overall

funding decision. Community reviewers serve a 2-3 year term, and review grant applications twice per year.

### CF Foundation Next Generation Patient Registry:



5 Community Voice participants.

The CF Foundation created a working group, including adults with CF, parents, and caregivers, as well as clinicians, researchers, and CF Foundation staff to participate in selecting a vendor as part of early planning phases for a new version of the CF Foundation's Patient Registry. The CF Patient Registry is critical to understanding trends in CF outcomes, improving care, and advancing research.

### CF Foundation Patient Registry and Modulator Ineligibility:



6 Community Voice participants.

The CF Foundation created a working group of adults with CF who are not eligible for modulators and parents/caregivers for those with CF who are not eligible to learn more about the clinical and demographic characteristics of people not eligible for modulators. Community members provided input on what information is important to gather about their health and experiences living without modulators, include their unique care needs and how their health has changed over time, including during the COVID pandemic. They also advised on the study analysis plan, study results (including how the data are presented), and the resulting draft publication, which is being submitted to a journal in early 2024.

## Care

### Screening for CF-Related Medical Traumatic Stress:



*2 Community Voice participants.* Researchers are still in the process of interviewing CF community members to create CF-specific criteria for medical traumatic stress (MTS) and create a diagnostic survey for MTS in CF patients that can be used in a clinic setting. These interviews are looking for triggers and symptoms of MTS and will be used to develop preventative and treatment strategies for MTS among those living with CF.

### Medical Traumatic Stress in Children with CF:



*4 Community Voice participants.* Researchers seeking to understand if and how the challenges that children with CF and their families are experiencing are related to medical traumatic stress created an advisory committee including three Community Voice members (one adult with CF and two parents of children with CF). These community members are reviewing draft interview questions and results, and will advise on proposed ways (or interventions) to help address medical traumatic stress in children with CF, with the goal of getting families support sooner and preventing medical trauma.

### CF Lung Transplant Consortium Steering Committee:



*2 Community Voice participants.* The CF Foundation's CF Lung Transplant Consortium (CFLTC) Steering Committee works to improve outcomes for people living with CF who are pursuing or undergoing lung transplant through quality improvement,

guidelines development, and research. The committee includes lung transplant physicians, clinical staff, and community members, and meets monthly. Two Community Voice members were selected to join the committee for a 2-year term each, alongside two community members already serving on the committee.

### Multiorgan Transplantation Experiences:



*2 Community Voice participants.* The CF Foundation interviewed community members with who have experienced more than one organ transplant (including lungs, kidney, liver, or pancreas) about their pre- and post-transplant care needs. Information gathered from these interviews will be used to inform Foundation materials to support individuals and families through the transplant process, including guidance and educational content about coordination of care. Interviews are planned to continue in 2024.

### Community Perspectives on Adapting CF Care:



*151 Community Voice participants.* People living with CF today are having a wide range of experiences with their health, which could impact the level and types of care they need over time. As some people are living longer, their needs are evolving and may become increasingly complex. For others, they may not be eligible for or able to tolerate modulators or their health may not have changed dramatically, so the care they receive may need to be sustained. The CF Foundation accredits care centers across the United States, and distributed a survey to learn how the care provided at those centers can better the evolving needs that people with CF and their families have. Results will...

## Care

### Community Perspectives on Adapting CF Care:

...be shared with the community in 2024, and will be used to inform guidance, education, and standards for CF care centers.

### Mind-Body Interventions for Pain Management:



14 Community Voice participants.

Researchers interviewed adults living with CF to better understand their experiences coping with CF-related pain. Community members noted they would encourage CF teams to listen and validate pain experiences in people living with CF. The results from these interviews were used to develop a CF-specific non-medication mind-body intervention for pain management, and will support a multi-center pilot trial of the intervention. Researchers expressed that the content and quotes from the interviews used in the materials for this approach help to destigmatize the topic and let community members know they are not alone in experiencing CF-related pain. Community members advised CF care teams to listen and validate their pain experiences so that people do not have to wait years to receive treatment for their pain.

### CF-Related Diabetes Bionic Pancreas Trial Advisory Group:



4 Community Voice participants.

Researchers developing an upcoming clinical trial convened an advisory committee to partner with CF community members. The community members are sharing their lived experiences with CF-related diabetes (CFRD) and advising on trial design, including how to make the clinical trial easier for people with CF to participate in. Their input is

shaping a multicenter clinical trial of the bionic pancreas, an artificial pancreas device that has been shown to improve blood sugar control in people with type 1 diabetes. Promising data support the safety and efficacy of bionic pancreas use in adults with CFRD, and community members serving on this advisory committee are supporting next steps to bring these types of treatments to the broader CF community.

### CF-Related Diabetes Spectrum Advisory Committee:



4 Community Voice participants.

Community members joined researchers and CF Foundation staff as part of the Spectrum Advisory Committee to better understand how CF-related diabetes (CFRD) impacts everyone with CF, especially among people of color and those who are not benefitting from modulators. The goal of the committee is to explore and address why people with CF may be hesitant to participate in studies related to diabetes. Input from community members is being used to help researchers design studies that are more practical for people with CF to participate in, including how things like study-related visits and testing are handled. The committee is also working to make information about these studies easier to understand to support greater participation and to advance research on to CF-related diabetes.

### Identifying Mental Health Challenges in People Living with CF:



22 Community Voice participants.

Researchers interviewed adults living with CF to learn about the community's mental health concerns and experiences. Information gathered during the interviews is being used to help shape considerations and develop...

## Care

### Identifying Mental Health Challenges in People Living with CF Continued:

...questions for a new, brief mental health screening tool tailored to people living with CF.

### Experiences with Inhaled Antibiotics and Pseudomonas:



Survey

*95 Community Voice participants.* Community members with *Pseudomonas aeruginosa* shared their experiences with inhaled antibiotic therapies through an anonymous survey, including whether they have used them before and preferences for their timing and use. The results will be used to inform CF care teams and the CF community on the preferences of inhaled antibiotic therapies to help the coproduction of care related to this medication type. Results of this survey will be submitted for publication in a peer-reviewed journal.

### Chronic Therapies for People on Modulators:



Committee

*6 Community Voice participants.* Researchers brought together community members (including adults with CF and parents or caregivers of people with CF) and clinicians on a working group to explore how they use or recommend chronic therapies based on CF care guidelines developed before highly effective modulator therapies. The group's input on related topics, such as how people make decisions to decrease or stop chronic treatments while on modulators, is being used to develop a clinical trial.

### Mental Health Working Group:



Committee

*3 Community Voice participants.* The CF Foundation's Prioritizing Research in Mental Health (PRIME) Work Group promotes

research that will improve the understanding, prevention, diagnosis, and treatment of mental health concerns in the CF community. Community members in the workgroup participate in standing team meetings, provide feedback on research priorities, and contribute to research discussions. The PRIME work group held its first strategic meeting in 2023, and will continue to meet virtually and develop plans for future grant applications related to CF and mental health, with the benefit of input from the participating community members.

### CF Care Model Committee:



Committee

*5 Community Voice participants.* Adults with CF and parents of children with CF joined the CF Foundation's CF Care Model Committee to share their perspectives on the traditional CF care model (quarterly visits to care center with PFTs, cultures, and visits with each multidisciplinary CF care team members). The committee plans to write a "position paper" to reflect changes to care needs that have occurred for many people with CF in recent years. Ultimately, the committee's work will lead to guidance for CF care teams on making modifications to the traditional CF care model when appropriate. This could result in a modified clinic visit schedule for some in the community, while making sure others continue to have their needs met.

### Prioritization of Sexual and Reproductive Health Topics:



Survey

*3 Community Voice advisors, over 300 survey respondents.* Three community members collaborated with researchers and CF Foundation staff on the development and design of a first-of-its-kind survey to understand the CF community's priorities...

## Care

**Prioritization of Sexual and Reproductive Health Topics Continued:**

...for sexual and reproductive health research and care. Over 300 community members shared their input on topics and areas they care the most about related to CF and sexual and reproductive health through this survey. The survey's results are being used to plan national studies focused on understanding and treating aspects of sexual and reproductive health in men, women, and all genders to improve quality of life and comprehensive care for all people with CF. Priorities identified through the survey are also guiding the work of the Sexual and Reproductive Health (SHARING) Working Group. Community members who are part of SHARING presented survey results at the spring 2023 meeting of the Therapeutics Development Network (TDN). Survey results were **published** (abstract #393) and shared during NACFC (see **59:08**).

**CF Sexual and Reproductive Health Resource Guide Updates (Mental Health, Modulators):**

Committee

5 Community Voice participants. Community members, all adults with CF, are collaborating on chapter revisions to the

**CF Sexual and Reproductive Health Resource Guide**, a free online resource for clinicians and patients designed to help facilitate conversations around sexual and reproductive health. The working group is adding information related to experiences with mental health and highly effective modulator use in chapters about body image, family planning, infertility, hormones, and more. Community participants include people with CF who identify as female and people with CF who identify as male. The

revised guide will be publicly available to the community in 2024.

**Supporting Discussions about Female Sexual and Reproductive Health for Adolescents with CF:**

Interviews

21 Community Voice participants. As people with CF are increasingly considering their reproductive goals, researchers are developing an online decision-making tool to address the sexual and reproductive health questions and concerns that adult women with CF may have. Parents of children with CF participated in interviews to help researchers understand the value or usefulness of the tool for adolescents and young adults who were assigned female at birth. Some teenagers with CF joined their parents in the interviews to share their perspectives. The results of these interviews will be used to shape future development of the tool.

**Reproductive Genetic Counseling for Adults with CF:**

Interviews

21 Community Voice participants. Researchers interviewed adults with CF – including parents, those thinking about becoming parents, and those who have decided not to become parents experiences with and awareness of prenatal and preconception genetic counseling. This included discussions of what supports and information would be helpful to receive as a part of CF-related reproductive genetic counseling, and learn whether genetics information has influenced decisions surrounding parenthood. Findings from these interviews will be used to develop an online reproductive decision-making tool and improve future clinical experiences for people with CF.

## Care

### Development of a Mobile App for Physical Activity:



Committee

1 Community Voice participant. Physical activity has shown to be beneficial to mental health, sleep, lung function, and quality of life to those with cystic fibrosis. Participating in regular physical activity becomes challenging during adolescence and early adulthood due to competing time demands, CF management, and other factors. A community member joined an advisory committee to support the development of a mobile app to provide adolescents and young adults with CF a feasible physical activity program. If the application is successful in encouraging physical activity in this population, researchers plan to expand it to the adult CF community.

### Shaping Materials on CF Growth Charts:



Focus Group

4 Community Voice participants. Researchers held a focus group in which community members shared their feedback on an infographic developed to better explain the different growth charts that may be referred to during clinic visits. Input shared during the focus group was used to revise the infographic, which is intended to inform and improve clinic discussions on growth trajectory in children with CF.

### Shaping Grants Related to Starting or Changing Therapies for Those Using Modulators:



Focus Group

28 Community Voice participants in 6 focus groups. The CF Foundation held focus groups as part of the Therapy Initiation and Modification in the ETI era (TIME) project to discuss starting, changing, or stopping preventative pulmonary-focused therapies

for individuals benefiting from Trikafta. Focus group participants shared what it means to be “stable” since they or their child started ETI, what their pre- and post-Trikafta treatment regimen looks like, and what guides them in making treatment decisions now that they are on ETI. Top community priorities for research data have also been incorporated into a list of “Areas of Interest” for researchers to focus on when applying to an upcoming CF Foundation grant related to the topic. *Although the focus groups and this particular funding opportunity is focused on research related to those who are eligible for modulators, the CF Foundation is continuing to prioritize, fund, and pursue research to help people with CF who are not currently benefitting from modulators.*

### Reviewing Grants Related to Starting or Changing Therapies for Those Using Modulators:



Committee

6 Community Voice participants. Following focus groups to help shape areas of interest for research, the CF Foundation recruited adults with CF or caregivers for people with CF for a committee to review clinical research grant proposals submitted by CF researchers requesting funding. Community members, alongside scientific reviewers, will evaluate proposals related to starting, changing, or stopping preventative pulmonary-focused therapies among individuals benefiting from Trikafta. Work reviewed and funded through this effort will help support evidence-based decision making on treatment plans. *Although this particular committee is evaluating grants focused on research related to those who are eligible for modulators, the CF Foundation is continuing to prioritize, fund, and pursue research to help people with CF who are not currently benefitting from modulators.*

## Care

### Prioritizing Male Sexual and Reproductive Health Topics:



Document Review  
or Written Input

8 *Community Voice* participants. Researchers recruited community members for an online activity to prioritize topics related to male sexual reproductive health and CF. Participants participated in brainstorming, rating, and sorting activities online. The research team will use the community's input from these activities to prioritize future research and develop new strategies to incorporate male sexual reproductive health topics into routine CF care.

### Use of Antibiotics or Other, More Tailored Approaches to Treating Mild Pulmonary Exacerbations in Children:



Focus Group

4 *Community Voice* participants in 1 focus group. Researchers studying the long-term safety and effectiveness of the use of oral antibiotics for mild pulmonary exacerbations compared to a more tailored approach in children with CF held a focus group with parents of children with CF. Community members shared their perspectives and concerns, including what

parents think about the need for antibiotic use for mild pulmonary exacerbations. The community input is being used to inform study design for trials to compare oral antibiotic use to alternative tailored treatments in children with CF. This is part of an ongoing series of work on Outpatient Treatment for Pediatric Pulmonary Exacerbations (STOP PEDS).

### Updating Cystic Fibrosis Transmembrane Conductance Regulator-Related Metabolic Syndrome (CRMS) Guidelines:



Document Review  
or Written Input

The CF Foundation CRMS Guidelines Committee, including health care providers with expertise in CF and CRMS and parents of children with CF, sought community input on draft guidelines related to CRMS. The previous guidelines were published in 2009, and the proposed revised version was shared with *Community Voice* members for their review. Community members provided written feedback on the guidelines via a survey form. The updated guidelines will take the community's input into account, and be published in 2024.

## Community

### Mary M. Kontos Care Champion Award Selection Committee:



Committee

2 *Community Voice* participants. The purpose of the Mary M. Kontos Care Champion Award is to honor CF clinicians who exemplify outstanding care to patients and families. Including the voice of patients and families in the award selection committee is important to ensure that the committee honors what the CF community considers

examples of great care. CF community members on the committee helped to select two award recipients from care centers located in the United States based on submitted nominations.

### CF Peer Connect Delayed Diagnosis Mentor Recruitment:



Other

10 *Community Voice* participants. CF Peer Connect and *Community Voice* teamed up to recruit new participants who are 40 years...

## Community

### CF Peer Connect Delayed Diagnosis Mentor Recruitment:

...and older and were diagnosed with CF as adults to serve as potential peer mentors to others diagnosed as adults. This resulted in new matches through CF Peer Connect, and helps ensure that relevant support is available to the community as new requests for connections arise.

### Community Voice Experiences Video:



Other

6 Community Voice participants. Community Voice members shared their experiences on various projects and how their partnership has made an impact on research, care, and programs for the CF community. The goal of the video is to help potential new members understand the power that their individual voices can have. The video was highlighted on the CF Foundation website and social media platforms, which led to the recruitment of new Community Voice members. The video and its excerpts have been viewed over 8000 times.

### CF Community Blog Survey:



Survey

89 Community Voice participants. Community Voice members gave feedback on the CF Community Blog that is hosted on the CF Foundation's website. All Community Voice members and those who have written for the blog gave feedback to help shape the direction of the blog and ensure it is best serving the community. The feedback will also inform future topics, the types of authors you hear from, and how the blog is shared with the community.

### Community Voice Spanish Sign-up Form:



Document Review  
or Written Input

3 Community Voice/Spanish Language Community Review Committee participants.

Members gave thoughtful feedback on the Community Voice Spanish sign-up form. Translating the sign-up form in Spanish was the first key step to making Community Voice available in Spanish. Participants also gave input on how the Community Voice team could spread awareness of the translated form. The sign-up form is now live for Spanish speakers to join Community Voice, although there are limited opportunities available we are continuing to grow the number in 2024.

### Compass Online Service Request Form in Spanish:



Document Review  
or Written Input

1 Community Voice/Spanish Language Community Review Committee participant. The CF Foundation's Health System Innovation and Navigation team collaborated with a Spanish-speaking CF community member to review a draft translation of the Compass Online Service Request Form. This community input helped ensure that the Compass request form – a major way that many individuals and families request help navigating a range of challenges associated with CF – is accurate and accessible for Spanish-speaking members of the CF community.

### CF Foundation Spanish Language Process and Style Guide:



Document Review  
or Written Input

3 Community Voice/Spanish Language Community Review Committee participants. Spanish-speaking community members supported the development of CF Foundation Spanish language process materials and a style guide. Their input on translating key terms and creating content for Spanish speakers has been key in enabling the CF Foundation to produce better resources and more consistent content for the Spanish-speaking CF community. These...

## Community

### CF Foundation Spanish Language Process and Style Guide Continued:

...documents will be regularly updated as things change to further meet the needs of the Spanish speaking community.

### NACFC Highlights – Webinar, Timestamps, and Q&A:



Document Review  
or Written Input

3 Community Voice/Spanish Language Community Review Committee participants. Bilingual community members reviewed the contents of the NACFC Highlights webinar originally presented in English to identify key moments to highlight in Spanish. Their input is being used to create a version of the event that is translated and accessible, including highlights and timestamps, to the Spanish-speaking CF community.

### Compass Resource Database Usability Testing:



Document Review  
or Written Input

10 Community Voice participants. Community members helped to test a draft version of the CF Foundation's Compass Resource Database, a new self-service tool to help people with CF and care team members find support resources. They reviewed a user guide and provided written feedback to inform the final version of the tool. The CF Foundation's Health Systems Innovation and Navigation team incorporated these insights and implemented changes in the **CF Resource Database**, which publicly launched in December 2023.

### CF Foundation Adult Advisory Council, Members and Chair:



Committee

7 Community Voice participants. The **Adult Advisory Council** was formed to serve as a consultative and advisory body to the CF Foundation on various areas and

activities, with a particular focus on issues of interest to adults with CF. Community members joined this rotating group to lend their voice to convey the hopes, needs, and aspirations of the CF adult community. These adult volunteer leaders provide feedback on various projects, including better ways the CF Foundation can partner with people with CF in key programs and events.

### CF Foundation NextBreath 2023 Planning Committee Co-Chair:



Committee

2 Community Voice participants. NextBreath is a free, online, two-day event for individuals with cystic fibrosis who are living with established lung disease, experiencing lung health complications, or have had a lung transplant, as well as their family members and caregivers. The CF Foundation's Community Conferences team partnered with Community Voice to recruit 2 adults to serve as co-chairs to work in partnership with CF Foundation staff to design, plan, and execute NextBreath. Recordings of the event are now live to **view** at your own pace.

### CF Foundation BreatheCon 2024 Planning Committee, Members and Co-Chair



Committee

11 Community Voice participants. BreatheCon is a free, online, community conference to gather with other adults with cystic fibrosis. The CF Foundation's Community Conferences team partnered with Community Voice to recruit adults with CF to serve as co-chairs and members of the 2024 program planning committee. BreatheCon will take place this year in February 2024. The eleven Community Voice members and five other community members who joined the BreatheCon planning committee played a huge role in shaping this event.

The mission of the Cystic Fibrosis Foundation  
is to cure cystic fibrosis  
and to provide all people with CF  
the opportunity to lead long, fulfilling lives by  
funding research and drug development,  
**partnering with the CF community,**  
and advancing high-quality, specialized care.



## Encourage others to join Community Voice!

If you know others who want to get more involved  
and help shape research, care, and programs,  
please encourage them to join by visiting  
[cff.org/CommunityVoice](https://cff.org/CommunityVoice).



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