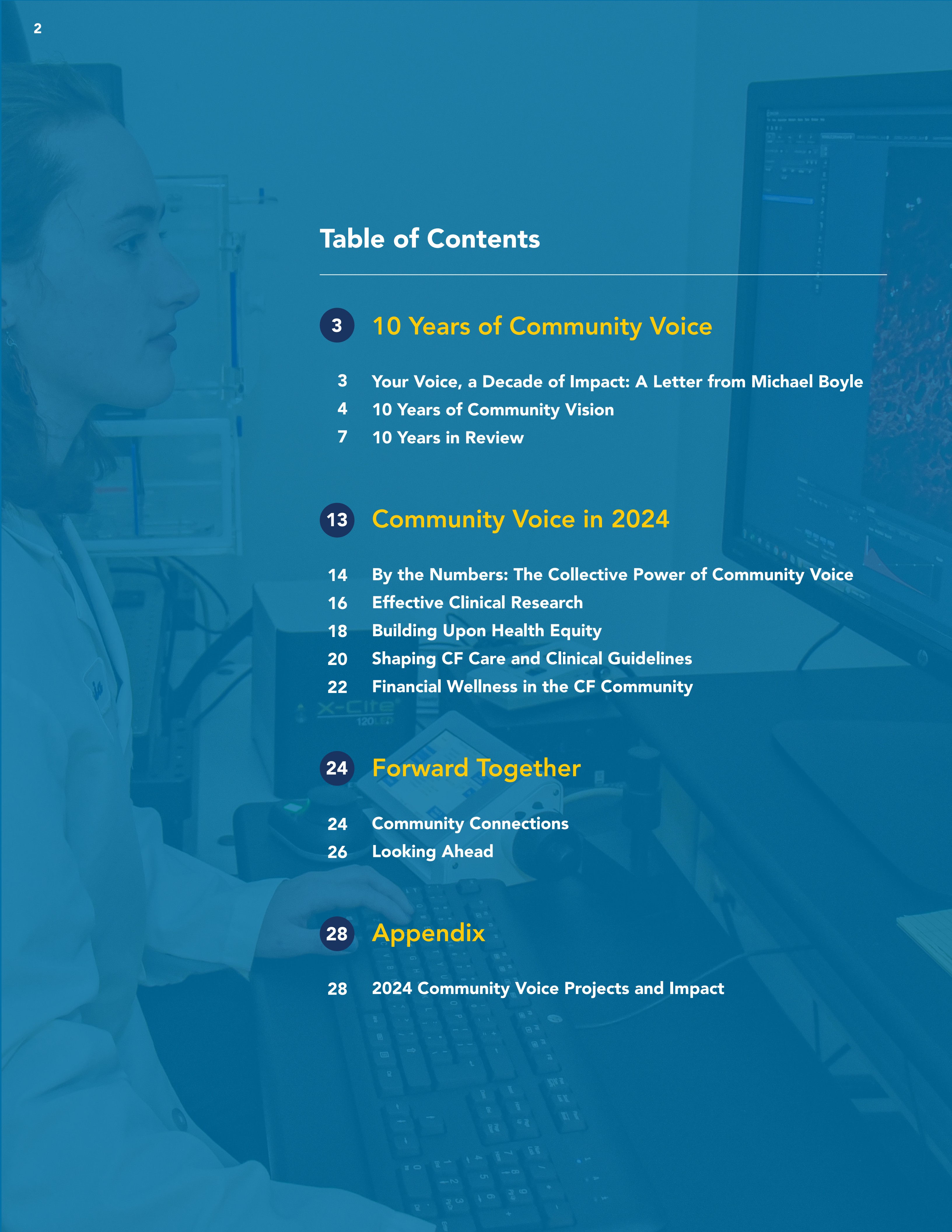
COMMUNITY VOICE

CYSTIC FIBROSIS FOUNDATION®

2024 Year in Review » A 10 Year Anniversary

YEARS OF COMMUNITY PROGRESS



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Your Voice
A DECADE OF IMPACT

As Community Voice celebrates 10 years, it is a great honor to look back at the many ways that you, the amazing CF community, have shaped research, care, and support programs through Community Voice.

More than a decade ago, the CF Foundation recognized a need to embed the **voice of our community in all we do** and launched Community Voice in December 2014 to facilitate that important partnership. Ever since, Community Voice has played a crucial role in driving our shared mission forward – from supporting **groundbreaking studies** in previously unexplored areas of CF research to contributing to **community-driven research and care across a wide range of topics.** Community Voice members have helped to set priorities for the Foundation and beyond, and sparked the creation of working groups and follow-on studies that yield real results for people with CF.

Through Community Voice, members also shaped **foundational programs** that today are a mainstay in the community, including CF Peer Connect and community conferences like ResearchCon and BreatheCon. In all, Community Voice members have made significant contributions to **more than 600 projects so far,** cementing the community's voice and experiences in research design, funding decisions, updates to care guidelines, and much more.

In 2024, Community Voice not only "turned 10," but celebrated another milestone as the program grew to more than 2,000 members strong. As we embark on our next Long-Term Strategic Plan, community input is more important than ever. People living with CF and their family members are having increasingly diverse experiences, and insights from our broad community remain an essential component to developing the next chapters of our work together.

Every time you share your experiences and perspectives through Community Voice, the path to a cure and to a better life for all people with CF today becomes clearer. I am excited to continue hearing from you, including new voices, and seeing how your expertise and dedication will make a positive and powerful difference for all people living with CF, including in ways we haven't even yet imagined.

With gratitude,
Michael Boyle, MD
President and Chief Executive Officer

YEARS OF COMMUNITY VISION

In 2014, the CF Foundation recognized that people with CF were living longer than ever and that the voices of the CF community were essential to keeping them at the heart of everything we do.

The Foundation launched Community Voice as a consultative body and partner to bring in the diverse lived experiences of people living with CF – and their parents and partners – to the forefront of planning and decision-making for future research, care, and CF-related programs.

In early years, Community Voice recruited members for the newly created Adult Advisory Council and other committees. Since then, Community Voice members have transformed CF research, care, and programs across **more than 600 projects.** Whether you're a long-standing member or one of our newer voices, your contributions have had — and will continue to have — a profound impact on improving the lives of those affected by CF.

First-of-its-kind research:

Community Voice has played a crucial role in supporting groundbreaking studies that investigate previously unexplored areas of CF research. Community input from early stages shaped work in emerging spaces, including digestive issues, when to use antibiotics, reducing chronic therapies and treatment burdens, pregnancy and CF outcomes, and monitor mental health and liver toxicity in new modulator Alyftrek.

Community-driven research and care:

When Community Voice was first created, members helped set research priorities for the Foundation and beyond. Ever since, Community Voice members have served as active partners to ensure research and care improvements are relevant and focus on the most significant areas to the CF community. These priorities sparked the creation of working groups and studies which led to research that otherwise might never have happened, including on mental health, sexual and reproductive health, infection research, social factors that affect health, and financial wellness.

Your input helps prioritize research that matters most to the CF community! The number of research proposals funded by the CF Foundation each year that are aligned with topics prioritized by the CF community has increased steadily over the past decade:

58%
as of 2017
(2013-2017)

84%
as of 2019
(2018-2019)

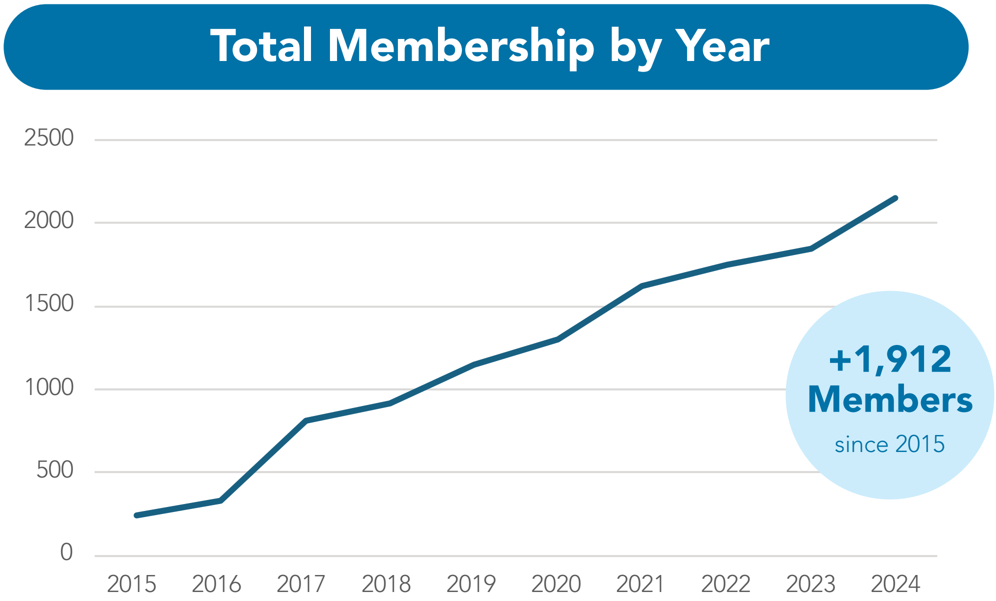
95%
as of 2024
(2023-2024)

As of 2017, 58% of research proposals funded by the CF Foundation in recent years were related to topics prioritized by the community. By 2019, 84% of funded research proposals were tied to community priorities. In 2023 and 2024, ***over 95% of funded research proposals aligned with community priorities,*** *including work on CF-related diabetes, mental health, modulators, bone health, telehealth, and more.*

Since 2020, Community Voice has received more than 1,000 community applications for 88 committee recruitments. In the last five years, 453 community members have served on committees.

Community-informed support and programs:

Support programs like CF Peer Connect and community conferences like BreatheCon and ResearchCon were initially developed with active input from Community Voice members, ensuring they meet the unique needs of the CF community. These programs continue to thrive today, thanks to ongoing contributions by and leadership from Community Voice participants.



Total Membership by Year

Community Voice now has a total of 2,100+ members

10 Years
IN REVIEW

December 14, 2014

Community Voice launches as "Adult and Family Advisors" (AFA) to serve as a consultative body and partner to the CF Foundation on various areas and activities, ensuring the ***community voice*** is in everything we do.

2015

- 🌐 AFA first recruits for the CF Foundation's **Adult Advisory Council** (AAC), a rotating group of adults with CF who partner with the CF Foundation to advise on a range of topics on behalf of the broader community.
- 🩺 The **Success with Therapies Research Consortium Steering Committee** launches, including members from AFA. It is the first group focused on helping people successfully manage complex care requirements, with the benefit of CF community input.
- 🔬 Members contribute to the design of a national study to **improve treatment of pulmonary exacerbations.**

TIMELINE CONTENT KEY

- 🌐 Programmatic/Organizational
- 👥 CF Support Programs
- 🔬 Research
- 🩺 Care

2016

Designed with input from Community Voice members, the CF Foundation launches its **Impact Grants program**, providing guidance and funding to individuals or programs actively working with and empowering the CF community.

Community Voice members participate in an advisory group for the **pilot and national expansion of a peer-to-peer mentoring program.**

The first-ever BreatheCon community conference is held following a Community Voice survey to shape the content. All content is prepared and delivered by adults with CF, including Community Voice members.

2017

AFA is renamed Community Voice in response to member feedback to reflect a need to ensure that *all* voices in the community are heard.

CF care guidelines committees are now encouraged to increase community representation by including at least two adults with CF and one parent to serve on each committee.

Community Voice launches the first-ever research prioritization survey, which shows that **just over half of research proposals** (58%) funded by the CF Foundation are aligned with CF community priorities. The CF Foundation starts recommending that researchers submit proposals that directly address community priorities.

2018

The CF Foundation launches the **Infection Research Initiative** in response to overwhelming community feedback identifying a need for additional research. Community members submit and vote on research priorities and speak up in focus groups to shape the $100 million initiative.

Members join the newly-formed **Spanish Language Community Review Committee** to help make more resources and projects broadly available to the CF community, including Spanish speakers.

Community Voice members inform study design on **GI wellness and reducing treatment burdens.**

Community members shape clinical care guidelines by joining committees on **Advanced Lung Disease and Palliative Care.**

2019

People with CF and family members start serving as community reviewers on the CF Foundation's **Clinical Research Committee**, advising on the feasibility and relevance of research proposals when making funding decisions.

The first-ever ResearchCon community conference is held, following Community Voice member support for planning and topic selection.

2020

The CF Foundation's mission statement expands to officially include **partnering with the CF community**, acknowledging the critical role community members play in the pursuit of our mission.

Recognizing that a wide variety of voices are critical to understanding the unique needs and experiences of every person with CF, the CF Foundation convenes a **racial justice working group** and increases focus on serving people with **rare and nonsense mutations of CF.**

Community members participate in the **Mental Health Research Prioritization Survey,** sharing insights on their experiences with anxiety, depression, treatment burdens related to CF. The results are used to ensure funding decisions for future work on mental health and CF are guided by the community's needs.

As more people with CF are re-evaluating their sexual and reproductive health choices, Community Voice members help shape future research on **childbirth, parenthood, and modulator use during pregnancy.**

Community Voice conducts focus groups and a national survey on **CF-Related Diabetes (CFRD).** Results show that the use of diabetes technology is growing but has not been well-studied and that related care experiences vary, leading to national conference sessions and a workshop to further CFRD research.

2021

Community members contribute to the CF Foundation's website redesign to improve user experience and ease of **access to quality information,** especially for those recently diagnosed with CF.

As COVID-19 continues to drive increased use of **telehealth and home-based research,** Community Voice members weigh in on remote symptom monitoring.

Community Voice members begin serving on the CF Lung Transplant Consortium Steering Committee, working to **improve lung transplant outcomes** and foster relationships between CF and transplant care teams.

2022

The CF Foundation publishes its **Communities of Color Report,** directly informed by Community Voice focus groups and survey responses, highlighting how race often affects every aspect of an individual's experience with CF.

Community members support the development of a new CF Foundation research funding opportunity to **advance health equity** in the CF population and join the **Clinical Research Executive Committee** for the first time.

More than 1,000 community members participate in the Wellness in the Modulator Era Survey about **how modulators are impacting physical and mental health,** financial wellbeing, and more.

2023

Community members advise on how to better screen for **mental health conditions**, prioritize CF mental health research, and prevent **medical traumatic stress** in adults and children.

People **not taking modulators**, including those not eligible or unable to take due to side effects, participate in one-on-one interviews, focus groups, and a research expansion committee to share how the CF Foundation can better support them and guide **genetic therapies research towards a cure.**

Community members contribute to funding decisions for emerging **CF health equity research**, including major work on CF newborn screening and how being a member of the LGBTQIA+ community relates to CF health outcomes.

2024

More than 1,100 community members complete a survey on the **burdens of CF health care costs.** [Survey results](#) drive planning for how to support the CF community and care teams in addressing financial challenges associated with CF.

Community Voice grows to **more than 2,000 members.**

Community members share their experiences with **newborn screening, delayed diagnosis, and nontuberculous mycobacteria (NTM)** to inform care guidelines, related educational materials, and advocacy efforts.

Parents participate in a full-day workshop and a related focus group on **CF carrier use of modulators during pregnancy** to reduce CF-related complications in children born with CF to prepare for future research and study design.

To help **shape the next long-term strategic plan** in 2026, the CF Foundation gathers input from more than 1,000 community members on their CF experiences, needs, and priorities. Preliminary results drive a follow-up survey in early 2025 to better understand people's experiences with **digestive issues and aging.**

"I wanted to get involved because I have a story to tell that can reach the Hispanic and Spanish-speaking CF community. I wanted to be and show that the CF Foundation is for all."

Elizabeth Guzman, parent of a child with CF

Why I PARTICIPATE

"I took part in research on men's reproductive health through Community Voice. The various things that turned out to be common for CFers was eye-opening, sometimes revelatory! Who knows how many other things are like this? And who better to ask than those of us with CF!"

Casey Bruce, adult with CF

By the 2024 NUMBERS

The Collective Power of the Community

Learn more about the impact members had throughout 2024 in our [Monthly Results Updates](). Missed out on projects you'd be interested in? Update your [profile]() and check out our [Share Your Voice page]() for open opportunities.

550+
Members completed at least one survey

4300+
Total survey responses submitted from across the CF community

212
Members served on 39 national committees/ workgroups

11
Committee recruitments that added 37 members in 2024 alone

Community Voice members participated in more than 35 opportunities, including:

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11 Health Equity

Projects focused on ensuring all people with CF have a fair and full opportunity to be as healthy as possible

9 Research and Cure

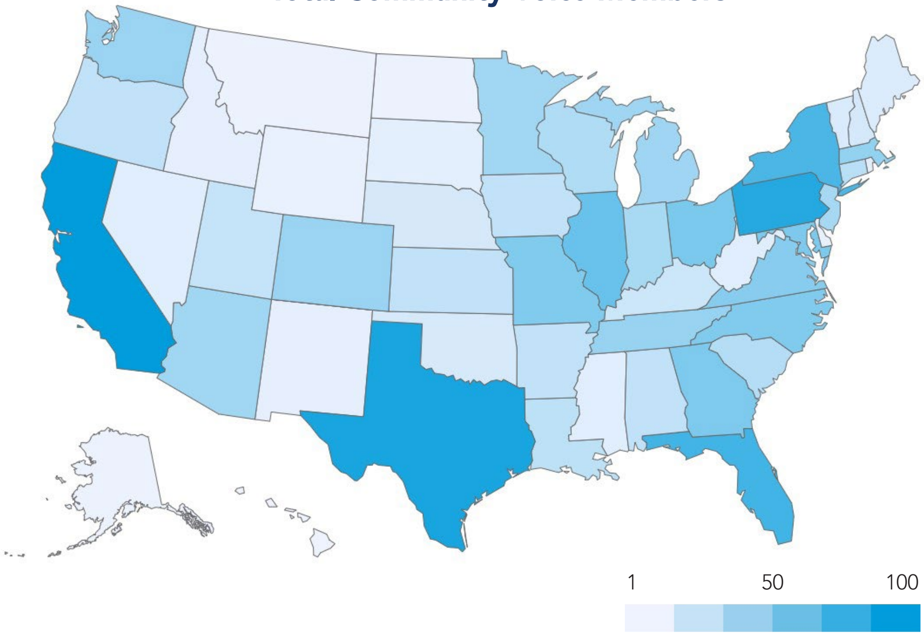
Projects focused on supporting research to advance new therapies and treatments

8 Community

Projects focused on expanding the reach of our programs and services to those in need

2,152

Total Community Voice Members



Members by CF Connection

45%
Person with CF

38%
Parent of a child with CF

26%
Other
(grandparents, siblings, children, aunts, uncles, in-laws, friends, etc.)

3%
Spouse of a person with CF

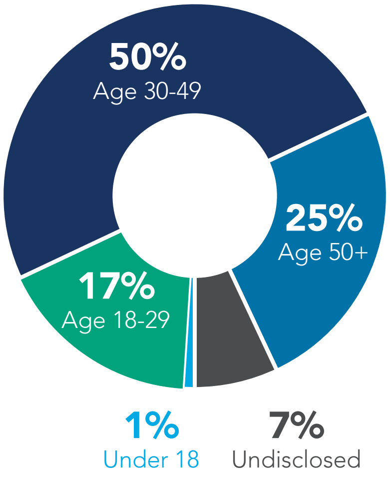
Every Voice Matters.

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:

People who identify...	in Community Voice	in the CF Found. Patient Registry*
as male	**23%**	**52%**
as a person of color	**8%**	**9%**
as Hispanic/Latino	**7%**	**10%**

** from Cystic Fibrosis Foundation Patient Registry 2023 Annual Data Report*

Members by Age



Effective CLINICAL RESEARCH

The CF Foundation backs a wide range of innovative research programs to identify and establish new and effective CF therapies. Through clinical trials, the ability to develop ground-breaking drugs and therapies for people with CF is possible. However, not all communities within the CF population have been represented in or served by research over time, and the CF Foundation and researchers are dedicated to closing the gaps.

In 2024, Community Voice members made significant contributions to this topic by sharing their perspectives to help improve clinical trials, including genetic therapy trials. You are helping to ensure these studies are inclusive and accessible, including people of color and those not eligible for or able to tolerate modulators.

- Researchers from the University of Washington recruited community members through Community Voice to serve on the **Equitable Participation in Clinical Research Steering Committee.** The group brought together people with CF, clinicians, and CF Foundation staff to explore how people of color are engaged in CF clinical trials to improve trial experiences. This committee informed the development of plans and questions for **follow-on interviews** with adults with CF who identify as Black and/or Hispanic about their experiences with clinical research, what makes it easier or harder for them to participate, and patient-centered solutions to improve inclusion.

- Additionally, the CF Foundation **interviewed people who do not benefit from modulators** to learn about the experiences of people of color with CF, including how they often do not receive clear information about CF research, their specific mutations, or genetic therapies.

Impact:

Through these and other projects, CF community members identified common concerns and barriers they face in participating in this research, like how a lack of representation of minoritized patients and staff at CF centers and in broader CF-related media contributes to a sense of isolation. Researchers and clinicians are also using community input to create guidelines on how to better support and improve the experiences of people of color participating in clinical research. The community learnings will continue to be used to help make studies – including genetic therapy trials for those not taking modulators – and other CF research information accessible to more people.

Up Next:

Research teams are continuing to review the insights shared by the community and will work closely with people with CF and their families to develop ways to support more equitable and inclusive participation in future clinical research and more effective information sharing.

Building Upon HEALTH EQUITY

Everyone with CF deserves access to timely diagnosis and high-quality care. To make that possible, we're taking steps to address known health care gaps. By addressing disparities ranging from delayed diagnosis to decreased access to care, we can help ensure all people with CF have fair and just opportunities to achieve optimal health outcomes. Learn more about why health equity matters in CF (video).

Health equity emerged as a crucial topic throughout 2024 across discussion groups, interviews, committee work, and surveys. Community Voice members continue play key roles in moving health equity work forward by serving on committees that allocate funding, advising researchers and clinicians on how to best design their projects, and then participating in the actual studies, ensuring CF community input is present throughout the entire lifecycle of the work.

- Since 2023, 20 community members have served as **grant reviewers for the CF Foundation's Health Equity Team Science Award** (HETSA), a funding program for clinical research projects that would make important contributions to improve health equity in the CF population.

- In 2024, **HETSA funded the PRIDE CF study** to better understand how the intersectionality of having CF and being a member of the LGBTQIA+ community may impact health outcomes. Through Community Voice, adults with CF and their family members participated in **online brainstorms, focus groups**, and **surveys** as part of PRIDE CF.

- More than 65 people with CF and parents of children with CF applied to join the HETSA committee to help make 2025 awards, demonstrating strong community interest in health equity and CF. The 10 community members selected reviewed applications for new work related to **health-related social needs, mental health, pollution, and sex differences** and CF.

Impact:

Community members having meaningful seats at the table where decisions are made ensures that the most critical health equity work moves forward. In particular, PRIDE CF is one of the first studies to consider how having any chronic disease and identifying as LGBTQIA+ affects people's lives. Community participation in these and other health equity projects will lead to better support for all individuals with CF as clinicians and the CF Foundation understand how best to serve people from many different backgrounds.

Up Next:

Community Voice will connect the CF community with relevant upcoming HETSA projects as they are funded and other ongoing health equity work – including opportunities to shape CF Foundation Long Term Strategic Planning.

Shaping CF CARE AND CLINICAL GUIDELINES

To support better health outcomes for people with CF, the CF Foundation sets guidelines for accredited care centers on a range of topics. These guidelines are developed based on the latest research, medical evidence, and consultations with experts on each topic, including significant CF community input. This often includes establishing a temporary committee to draft a position paper or guidance, followed by a public comment period when clinicians and the community share input on the draft guidelines.

In 2024, Community Voice members responded to draft guidelines on three topics and joined two committees starting work on other guidelines.

- Community Voice recruited community members to serve on the CF Care Model Committee to help reevaluate the traditional CF care model, including quarterly care visits with pulmonary function tests (PFTs) and other testing. Participants helped draft two position papers recognizing **recent shifts in CF care**, which Community Voice members provided feedback on. Both position papers on the **CF care model** and **CF care teams** were published in November 2024.

- The CF Foundation convened an interdisciplinary committee to develop new guidelines to address **pain management in CF** and recruited adults with CF and a parent of a child with CF through Community Voice to serve as advisors. More than 40 community members provided input on the draft guidelines, which were finalized and **published** in December 2024.

- The CF Foundation's Newborn Screening Steering Committee developed new guidelines to improve health equity, sensitivity, and timeliness in **diagnosing babies with cystic fibrosis** to improve health outcomes and minimize disparities. Three community members actively served on the committee and more than 20 others from Community Voice provided input on the draft guideline or shared personal stories to support advocacy for the new policies. The **final guideline** was published in April 2025.

Impact:

Community input on guidelines and position papers has ensured that the CF Foundation's recommendations are in line with real life experiences of a broad range of people living with CF.

Up Next:

The CF Foundation will be seeking community comments on draft position papers or guidelines related to sexual and reproductive health, infection prevention and control (IPC) in clinical settings, and nontuberculous mycobacteria.

Financial Wellness IN THE CF COMMUNITY

As many people with CF are living longer, some are working more, aging off parents' insurance, raising families, or otherwise planning for the future — all of which come with financial considerations. Financial wellness — or being able to meet financial needs and manage personal finances to reach your goals — can be a challenging aspect of life with CF.

In 2024, Community Voice members participated in several key projects focused on better understanding finances and related supports for people with CF and their families:

- Community members serving on the **Financial Wellness Advisory Committee** advised the CF Foundation on how people living with CF currently meet needs for money, absorb unexpected costs, and financially plan for the future. They helped prioritizing financial wellness topics for further exploration, including developing a major survey on CF cost burdens.

- More than 1,100 people with CF, parents, and caregivers shared their experiences with health care costs as part of the **CF Outcome, Social Factors, and Tradeoffs Due to Coverage and Financial Burden (COST-CF) Survey.** The survey showed that nearly 70% of people with CF experienced a financial challenge due to CF-related medical bills, and more than one-third of people with CF delayed an aspect of their CF care due to medical bills in the last year.

- **Young adults with CF transitioning to financial independence** participated in interviews, in which they defined financial wellness as wanting to stay afloat, setting goals of being comfortable and responsible with money, and having a full life. They also identified barriers to these goals, like not knowing all of the costs related to CF care, not having savings, or working a job that barely covers expenses.

Impact:

Community insights on financial wellness are being used to develop educational materials and resources to better support financial security for people with CF and their families. They are also being used to support future research and ongoing advocacy for Medicaid and other programs.

Up Next:

Community members who have experience with CF influencing their decision-making about employment are partnering with the CF Foundation to develop educational materials and strategies to support improved financial wellness for people with CF and their families.

Members of the Adult Advisory Council

Forward Together

COMMUNITY CONNECTIONS

Community Voice members also contribute to programs and efforts to strengthen connections virtually across the CF community. Here are just a few ways in which the CF community came together in 2024, including contributions made by dozens of Community Voice members.

Shaping and Hosting Community Conferences

Community Voice members co-chaired and helped plan two major online community conferences in 2024:

- Over 230 adults with CF came together for the two-day **BreatheCon 2024** conference on the theme "My CF Journey," with a focus on how individual experiences with CF can vary widely and welcoming newcomers to the online space and community.
- **ResearchCon 2024** drew nearly 500 attendees, mostly people with CF and parents, and spotlighted research in liver disease, pain management, and more. New roundtable discussions supporting direct conversations between clinicians, researchers, and the CF community as well as social lounges were developed with extensive community input.

More than 10 Community Voice members worked to plan and host BreatheCon 2025 (February 7-8) and ResearchCon 2025 (May 6). **Learn more about community conferences here.**

Supporting Each Other Through CF Peer Connect

Many 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 2024, Community Voice helped recruit parents of young children with CF (ages 5 and under) to serve as potential peer mentors to other parents with young children. **Read more about CF Peer Connect or request support.**

Building Community Through CF Circles

In 2024, the CF Foundation launched CF Circles, small group discussions where members of the CF community – primarily adults with CF – gather virtually to talk about their unique experiences. These hour-long discussions each focus on a specific topic, such as not benefitting from modulators, receiving a delayed diagnosis, living as a Black person with CF or living longer with CF. Community Voice members have actively attended and helped to facilitate sessions. **Get involved with CF Circles.**

Consulting on the Adult Advisory Council

The **CF Adult Advisory Council** (AAC) welcomed four new members from Community Voice in 2024. The 10-member council reviewed community submissions for **Impact Grants**, advised on the North American Cystic Fibrosis Conference (NACFC) streaming content, and assessed the CF Foundation's mission statement as part of long-term strategic planning.

Forward Together

LOOKING AHEAD

Over the first decade of partnership through Community Voice, the CF community has contributed to hundreds of projects and initiatives that have had – and will continue to have – significant impacts for people living with CF.

We are excited and ready to support continued CF community insight gathering to ensure the CF Foundation – and related research and care – keep sight of what really matters: the lives, priorities, and well-being people with CF and their families.

Here are just some of the ways we anticipate community perspectives to drive progress in 2025 and beyond:

Key Areas for Community Input

Mental health and CF

Infection prevention and control in clinical settings

Developing resources to support care coordination

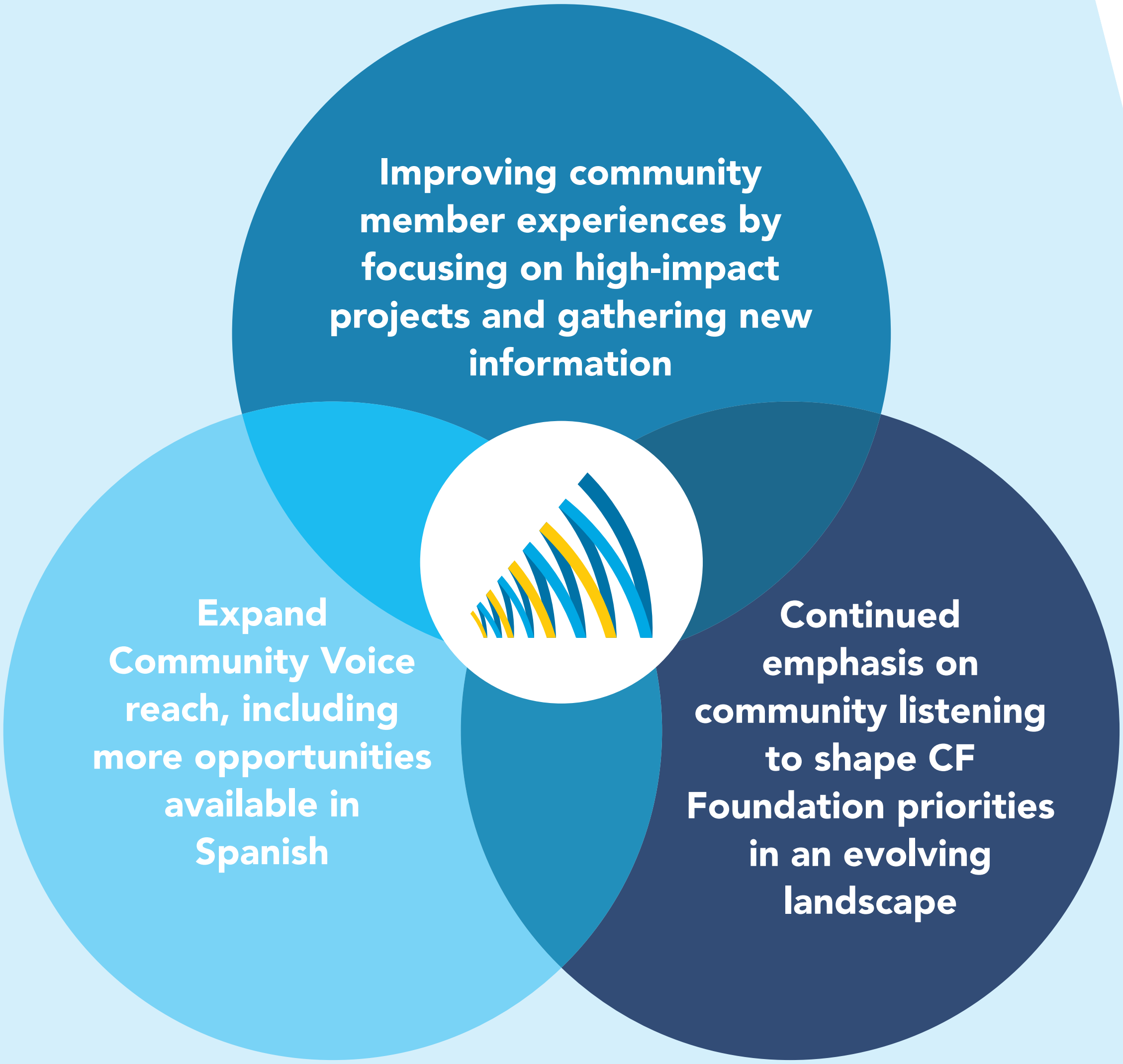
Supporting new drug development and research

Living longer and navigating new challenges with CF

Digestive health and metabolism, including GI symptoms, CFRD, and nutrition

Nontuberculous Mycobacteria

Sexual and reproductive health



Improving community member experiences by focusing on high-impact projects and gathering new information

Expand Community Voice reach, including more opportunities available in Spanish

Continued emphasis on community listening to shape CF Foundation priorities in an evolving landscape

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2024 APPENDIX

Community Voice supported a wide variety of projects in 2024. We are excited to share the many ways you had an impact in this appendix.

HE Health Equity Related

* Offered in Spanish

Informing the CF Foundation Long Term Strategic Plan*

Survey · 1,105 community participants, including Community Voice members

To help shape the next chapter of its work, the CF Foundation launched a survey to identify the needs and priorities of the CF community. Nearly 2,000 people – mostly people with CF and their family members, joined by researchers, clinicians, and volunteers – completed the survey, the results of which are already being used to inform strategic plans for the next five years to drive continued progress across cure, care, and community initiatives. Based on preliminary results, the CF Foundation created a follow-on survey to better understand community experiences with digestive issues and aging with CF. Full results of both surveys will be available in 2025 and used to develop the new strategic plan starting in 2026.

> **"The invaluable input from the CF community through the Long-term Strategic Plan survey has been shared with executive leadership and the National Board of Trustees, guiding our priorities in research and care. This feedback has kept us focused on the evolving needs of people with CF, ensuring our plan for the next five years addresses top concerns such as care coordination, and ultimately, driving progress towards a cure. We are deeply grateful for the community's time and expertise."**
>
> Marin Goings, SVP Chief of Strategy, CF Foundation

Cure & Research:

HE Experiences of People of Color Living without Modulators

Interviews · 10 Community Voice participants

To better understand the experiences of people of color, including those who are living without modulators, CF Foundation staff interviewed adults with CF and parents of children with CF who are not able to benefit from modulators either because they are not eligible due to mutation or not able to tolerate modulators due to side effects. These interviews were a follow-up to the 26 interviews conducted in 2023. Insights gathered from all the modulator ineligible interviews are being used to support the development of effective and accessible clinical trials, programs, and other support that will benefit the entire CF community, with a particular focus on those not benefitting from modulators.

HE Health Equity Team Science Award Community Grant Reviewers

Committee · 10 Community Voice participants

In 2024, more than 60 people applied to serve as community grant reviewers for the Health Equity Team Science Award (HETSA), a CF Foundation funding program for clinical research projects making important contributions to improve health equity in the CF population. This year's ten community participants reviewed applications, drawing on their own lived experiences and observed community-wide experiences to provide patient perspectives, share priorities, and identify possible barriers to community participation in studies. With the benefit of community input, HETSA funded research on health outcomes for transgender people with CF, data-driven study of health disparities in CF, and how harmful chemicals in the environment and food insecurity impact people with CF.

HE Equitable Participation in Clinical Research Steering Committee

Committee · 2 Community Voice participants

Researchers recruited Black and Hispanic adults with CF to join clinicians and CF Foundation staff on a steering committee to improve engagement of people of color in clinical research. Community participants provided valuable insights on the overall project plan and helped develop an interview guide to get additional community perspectives. The committee's work and subsequent interviews are shaping efforts to increase representation across all backgrounds in CF clinical research by better understanding the experiences of people of color with CF, including barriers they may face to participating in such research.

HE Equitable Participation in Clinical Research Interviews

Interviews · 12 community participants, including 5 Community Voice members

Researchers used the interview guide developed by the Equitable Participation in Clinical Research Steering Committee to interview people with CF who identify as Black and/or Hispanic about their experiences with clinical research, what makes it easier or harder for them to participate, and potential solutions to improve inclusion. The learnings from these interviews are being used to improve future research and care to support more inclusion and equitable participation in clinical trials.

Cure & Research:

Prenatal Modulator Treatment to Prevent CF Complications

Workshop · 5 Community participants, including 4 Community Voice members

Researchers are exploring how modulators may be used by people who do not have CF (but are pregnant with or breastfeeding a child with CF) to prevent or reduce CF complications in these children. People who are both CF carriers and parents to children with CF participated in a full-day CF Foundation workshop. They reviewed ongoing research, identified potential risks, and discussed considerations for research and study design. Results from the workshop will drive research priorities and assist in the development of eventual guidance for treating CF with modulators during pregnancy.

Modulator Effects Throughout Pregnancy for CF Carriers

Focus Group · 10 Community Voice participants

Parents of children with CF participated in a focus group to share their perspectives as carriers of CF on using modulators during pregnancy to prevent CF-related complications in a child with CF. Topics included parents' interest in or concerns about taking modulators while pregnant and their comfort level with newborn participation in research studies, including blood draws. Researchers are using findings from the focus group to inform the design of a study to set modulator dosing levels for CF carriers when pregnant. The follow-on study will support the development of broader "on-label" prescribing guidelines, which could help expand insurance coverage for modulator use by CF carriers pregnant with a child with CF.

HE Patient-Provider Communication and Trust

Focus Group · 10 Community Voice participants

People with CF and parents of children with CF shared their opinions on how to facilitate difficult conversations, create collaborative treatment plans, and build greater trust between people with CF and providers. Researchers are working to understand how to support more open and effective communication between people with CF and clinical staff. Focus group findings are being used to improve communications in care settings, including creating a way to measure the strength of these communications and the quality of patient-provider relationships.

Breath Sampling at Home

Survey · 107 Community Voice participants, 27 CF Canada Elevate participants

This survey was a collaboration between researchers, Community Voice, and CF Canada's Elevate program. It included an embedded video demonstration of how breath samples could be collected at home. Community members in the U.S. and Canada shared their thoughts on providing at-home breath sampling for remote monitoring. While researchers are still working to identify the biomarkers (or indicators) for the types of bacteria and infections that may be detected in breath samples in people with CF, **community input on potential breath sampling at home** will directly inform the design of future studies and testing. Collecting breath samples at home could reduce the need for in-clinic visits, enable remote participation in research studies, or serve as an alternative to sputum sampling.

Cure & Research:

Reducing Early Airway Clearance Treatment in Children

Focus Group · 9 Community Voice participants

Parents of children with CF provided input on key features of the design of a national, multicenter clinical trial that will evaluate whether it is safe to stop or to not start chronic daily inhaled therapies (such as Pulmozyme or hypertonic saline) in children 3 to 12 years of age who are doing well on Trikafta. Based on community and care team input, researchers significantly redesigned the study to include checking lung function before and after initially stopping therapies to address safety concerns.

> **"The parents' input was phenomenal. They had a variety of opinions and were thoughtful advocates for research. I can't thank them enough for the time they took – their recommendations had a large impact on our design!"**
>
> Margaret Rosenfeld, MD

Care:

HE

Burden of Health Care Costs on the CF Community*

Survey · More than 1,100 community participants, including Community Voice members

People with CF and their family members shared their experiences with CF-related health care costs and how those costs impact their lives as part of the CF Outcome, Social Factors, and Tradeoffs Due to Coverage and Financial Burden (COST-CF) Survey. The **initial results show** widespread challenges that people with cystic fibrosis face in managing health care expenses, including difficulty paying for insurance, food, or housing. The CF Foundation is continuing analysis of survey responses and is using the information to better support the CF community and care teams in addressing financial issues associated with CF. Additional results will be shared in 2025.

Redefining the CF Care Model and CF Care Team

Document Review, Written Input · 79 community participants provided public comments

In partnership with the CF community and clinicians, the CF Foundation updated guidance on **how and when routine care is provided** and the **structure of CF care teams.** The updates recognize the diversity of experiences and needs that exist within the CF community and encourage care teams and families to work together to adapt their care to support individual priorities and well-being. The CF community informed the development of the new guidance in past years through focus groups, surveys, and a committee. In 2024, the CF community provided feedback on the draft guidance. See **Redefining the CF care model** and **Redefining the CF care team** for the published guidance, which is starting to be implemented.

Care:

HE

Experiences with Trust and CF Care

Interviews · 35 participants, including 22 Community Voice members

Researchers interviewed adults with CF and parents of children with CF to better understand trust dynamics between people with CF and clinicians, including how they have experienced trust or a lack of trust in care settings. Audio and video recordings from the interviews are being used as part of care team trainings to show what builds or hurts trust to improve CF care experiences. Published results include articles about trust and **new clinic experiences**, **how trust experiences vary widely,** and the **strong Community Voice interest in trust research.**

> **"I'm grateful that so many people from the CF Community from diverse backgrounds and identities were willing to share their experiences with trust. Their authentic accounts, examples, and insights create a rich library that encourage healthcare providers to consider new ways of partnering."**
>
> Stacy Van Gorp, PhD

HE

Living with CF as Member of the LGBTQIA+ Community

Focus Group · 39 community participants, including Community Voice members

Members of the CF community who identify as LGBTQIA+ participated in an **online brainstorm** to list, rate, and sort their priorities related to their experiences and life with CF. Researchers held a follow-on focus group to discuss priorities and hopes for future research in detail. Results highlighted **health care and social challenges.** This work is part of PRIDE CF, an ongoing multi-institution effort to learn more about and incorporate LGBTQIA+ experiences into improving routine CF care for people of all backgrounds and experiences.

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National PRIDE Study and CF

Survey · More than 40 community participants, including Community Voice members (enrollment ongoing).

PRIDE CF is the first national long-term health study of people with CF who identify as LGBTQIA+. People with CF who have joined the study will complete two surveys each year, with the option to join additional CF-related surveys and individual interviews. PRIDE CF aims to fill in gaps in understanding around how identifying as LGBTQIA+ impacts a person's health, and will support the development of strategies and practices to improve health outcomes for all people with CF.

HE

Race-Neutral Pulmonary Function Test (PFT) Changes

Focus Group · 6 Community Voice participants

In 2024, the CF Foundation changed the way it reported lung function of people with CF in its Patient Registry by no longer using race as a factor for lung function data, including Pulmonary Function Tests (PFTs). People with CF and parents

Care:

of children with CF shared their perspectives as members of the Black CF community to shape communications to patients explaining the changes in how PFT results are reported. The community feedback directly informed a **patient handout** and a discussion guide to support care team and patient conversations on the changes.

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Comprehensive CF Newborn Screening

Document Review, Written Input · 13 Community Voice participants provided public comments

A CF Foundation committee including parents of children with CF developed draft recommendations on the best way for CF newborn screening to be performed and how newborn screening labs should notify clinicians of a positive result. Community members provided feedback on the new technical guidelines to ensure they aligned with community perspectives, in addition to published scientific research. The guidelines aim to support more comprehensive newborn screening, which is necessary for a timely diagnosis and the first step for everyone with CF to live healthier and longer lives. **The published guidelines** are technical in nature, as they are written for personnel who work at state public health labs that perform newborn screening tests.

Addressing Pain in People Living with CF

Document Review, Written Input · 40 community participants provided public comments

The CF Foundation sought feedback from the CF community on a draft guideline on addressing pain in people living with CF. Community members provided input on the guidelines, which call for a collaborative approach between CF care teams and specialists to effectively treat pain. The **published guidelines** also support the development of individualized treatment plans that use a combination of different approaches to addressing pain.

Intimate Partner Violence and CF

Survey · 55 Community Voice participants

People with chronic health problems may be at higher risk of intimate partner violence in some situations. Researchers surveyed people with CF and their family members to understand their willingness to participate in related research about their own experiences (if any) with intimate partner violence and what the community knows about related resources or screenings in CF care settings. **The results** will be used to shape a potential future survey on intimate partner violence and CF, which could support the development of a screening tool for use in clinics.

Care:

Nontuberculous Mycobacteria Guidelines Committee and Experiences

Committee · 30 Community Voice participants, including 3 committee members

The CF Foundation's newly-established Nontuberculous Mycobacteria (NTM) Guidelines Committee, including community representatives, will review and update existing guidelines for how NTM infections are treated in people with CF. In addition to joining the committee, Community Voice members shared their experiences with being treated for NTM to help inform the committee's work.

CF Foundation Lung Transplant Advisory Group

Committee · 19 Community Voice participants

The new CF Foundation Lung Transplant Advisory Group will provide community guidance and insight to shape the Advanced Lung Disease and Lung Transplant Research Program's work. In 2025, the group will develop and put into action a strategic communication framework to improve outreach to those who have undergone a lung transplant and their caregivers and family members. This will include improving how information is communicated and improving resources for those who are post-transplant. For more information, see the Advanced Lung Disease and Transplant Program's **2024 Year in Review report.**

CF Foundation Education Committee

Committee · 2 new Community Voice participants

Adults with CF and parents of children with CF serve alongside clinicians on the CF Foundation Education Committee. This group works to expand knowledge about cystic fibrosis by developing and standardizing educational materials for patients, families, health care providers, staff, and volunteers. In 2024, the committee reviewed and approved a wide range of educational materials, including a **Birth Control Guide for People with CF**, the **CF-Related Diabetes Manual**, information for people **transitioning from pediatric to adult care,** and more.

Financial Wellness for Young Adults with CF

Interviews · 4 Community Voice participants

Young adults with CF in different stages of transitioning to financial independence participated in one-on-one interviews to share their perspectives on financial wellness. They defined what financial wellness meant to them, including wanting to stay afloat, setting goals of being comfortable and responsible with money, and having a full life. Input from these interviews, in combination with ongoing work by community members on the Financial Wellness Advisory Committee, guided the development of a video series on **Navigating the Costs of Care as a Young Adult,** a guide on **Financial Considerations for Young Adults with CF**, and a **budgeting and planning worksheet** for young adults' life needs and health care costs.

Sexual and Reproductive Health Position Paper Committee

Committee · 3 Community Voice participants

Adults with CF and the parent of a teenager with CF, representing both male and female perspectives, joined a CF Foundation committee to develop a position on sexual and reproductive health topics and CF. The community members joined CF staff and researchers in reviewing recently published research to develop guidance on topics like contraception, fertility and infertility, and pregnancy (including fetal effects

Care:

of modulator use while pregnant). Once shared with the CF community in spring 2025 for public comments, the published position paper will support effective CF care related to sexual and reproductive health.

Sexual and Reproductive Health Guide Updates on Mental Health and Modulators

Committee · 5 new Community Voice participants

The Cystic Fibrosis Reproductive and Sexual Health Collaborative (CFReSHC) brings together patients, clinicians, and researchers working together to improve sexual and reproductive health knowledge, resources, and standards of care for people with CF. Their **CF Sexual and Reproductive Health Guide** is created by people with CF to help facilitate conversations between providers and patients on a range of topics. Over the last two years, the CFReSHC team, in partnership with Community Voice members, has updated the guide with new information about the intersection of mental health and modulators with each topic it covers. In 2024 and 2025, the working group will update additional chapters on menopause, incontinence, vaginal health, and sex, gender, and sexuality.

CF Medication Types Survey

Survey · 215 Community Voice participants

Community members shared feedback on taking different medications (including hypertonic saline, antibiotics, and modulators), vaccines (such as COVID-19 and flu vaccines), and future genetic therapy treatments. Results from the survey are being used to educate clinicians about community preferences on various treatments, with the goal of encouraging clinicians and people with CF to engage in shared decision-making about care, especially for current and new medications and therapies.

Impact of CF on School Experiences

Survey · 146 community participants, including Community Voice participants

The CF Foundation and Cincinnati Children's Medical Center surveyed adults with CF and caregivers of children with CF to better understand how CF impacts students' school experience. The survey explored topics like attendance, relationships with teachers and peers, and advocating for CF-specific needs to shape the development of new resources and interventions to support school success for those living with chronic health conditions, including CF.

> **"Over the last 10 years, it's been wonderful to see that members of Community Voice have shared their stories and perspectives. Their contributions have helped us address critical topics that impact health equity, such as improving newborn screening, and tackling complex issues that get in the way of being able to access high-quality care. We are so grateful to everyone who lend their voice to share the diverse needs and perspectives of our community."**
>
> Mary Dwight, SVP Chief of Policy & Advocacy, CF Foundation

Care:

CF Patient Registry and Medicaid Database Analysis

Focus Group · 7 Community Voice participants

Community members provided feedback on a research proposal to examine data related to experiences with Trikafta by comparing information from a national Medicaid database and the CF Foundation Patient Registry. The research would include an analysis of side effects (including liver problems and changes in mental health) and health outcomes among people taking Trikafta who stop taking other medications.

Mental Health Advisory Committee

Committee · 1 new Community Voice participant

A parent of a preteen with CF joined two people with CF serving on the CF Foundation Mental Health Advisory Committee (MHAC). This group works to promote and support the mental well-being of people with CF and their families by partnering with CF care centers to provide screening, prevention, and related services. Community members work with others on the committee to develop and review resources on CF and mental health that are available to the community on the CF Foundation website and through their care teams.

Success with Therapies Research Consortium Steering Committee

Committee · 3 Community Voice participants

Recognizing how hard CF daily care can be and the importance of keeping up with therapies, the Success with Therapies Research Consortium Steering Committee oversees clinical studies to identify what gets in the way of daily care and to test solutions that are effective, practical, and sustainable. Steering committee members give investigators feedback on research questions, study design, and interventions, and contribute to decision making about the operations and policies of the consortium.

Community:

CF Foundation Adult Advisory Council

Committee · 4 new Community Voice participants

The CF Foundation's **Adult Advisory Council** serves as a connection between the adult CF community and the CF Foundation. In 2024, four Community Voice members joined seven adults currently serving on the council. Members lend their voices to convey the hopes, needs, and aspirations of the CF adult community by tapping into their strengths and expertise of other community members. The Council provides advice with a focus on the perspectives of adults living with CF directly to senior leadership of the CF Foundation and its Board.

Community Support Grant Review Committee

Committee · 4 new Community Voice participants

Community members joined the CF Foundation **Community Support Grant** Review Committee to evaluate funding applications for community-led programming. Community Support Grants are funded by the CF Foundation, and are awarded to previous Impact Grant recipients to continue to grow the ways they support people with CF and their families. The committee evaluates applications to ensure they demonstrate a high standard of service to the CF community and provides funding recommendations to the CF Foundation's Community Partnerships department.

Selecting Conference Livestream Sessions

Survey · 145 Community Voice participants

CF community members prioritized which research and care-related sessions should be livestreamed during the 2024 North American Cystic Fibrosis Conference. The six sessions the community chose were broadcast live during the conference, spanning topics like living longer with CF, bone health, and keeping new CF treatments affordable. Most NACFC sessions, including those that were not livestreamed, are available to **watch online**.

BreatheCon 2025 Planning Committee

Committee · 14 community participants, including 10 Community Voice members

People with CF partnered with the CF Foundation's Community Conference team to plan and host **BreatheCon 2025**, a free, online, community conference to gather with other adults with cystic fibrosis, in February 2025. BreatheCon planning committee members designed programming, selected topics, and supported outreach to spread the word about the conference. Recordings are available to **watch online**.

Peer Connections for Parents of Young Children with CF

Community Support · 5 new Community Voice participants

Community Voice teamed up with the CF Foundation's **Peer Connect program** to recruit parents of young children with CF (ages 4 and under) to serve as potential peer mentors to other parents of young children with CF. This resulted in new matches through CF Peer Connect and helped ensure that relevant support is available to the community when new requests for connections are made.

Community:

Spanish Language Community Reviews*

Document Review, Written Input · 4 Community Voice participants

Community members who speak both English and Spanish reviewed draft surveys, Community Voice communications, and other draft content in Spanish as members of the Spanish Language Community Review Committee. Their work helps to ensure that Spanish communications are accurate and culturally appropriate.

Community Survey Reviews

Document Review, Written Input · 15 Community Voice participants

Community members reviewed draft surveys as part of the ongoing Community Survey Review Group. Participants tested both the content and experience of taking the surveys. CF Foundation staff and outside researchers used their feedback to streamline and improve their surveys to make them easier and shorter, or added questions to better understand the nuances of community experiences living with CF.

Thank you for your time and participation, from the entire Community Voice team!

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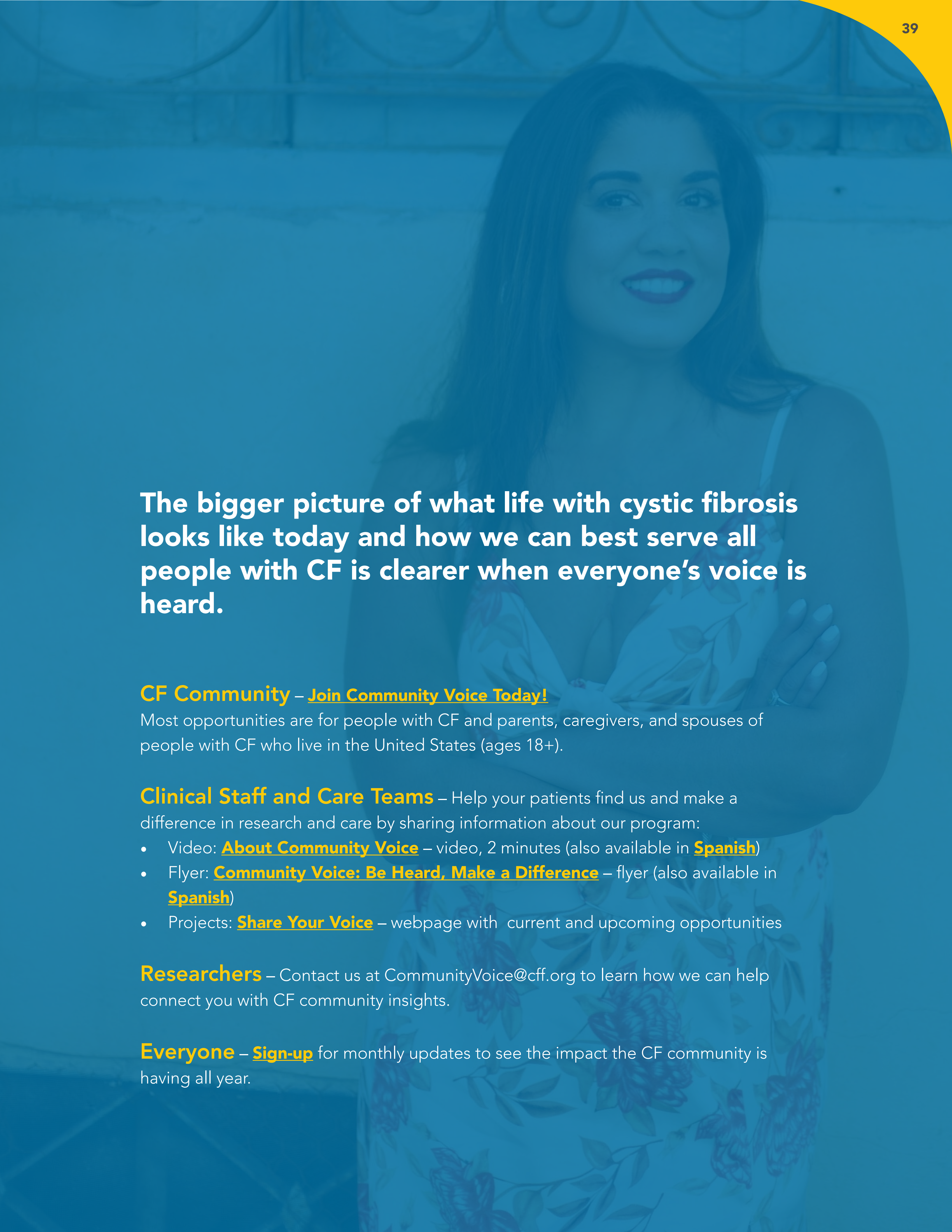

The bigger picture of what life with cystic fibrosis looks like today and how we can best serve all people with CF is clearer when everyone's voice is heard.

CF Community – **Join Community Voice Today!**
Most opportunities are for people with CF and parents, caregivers, and spouses of people with CF who live in the United States (ages 18+).

Clinical Staff and Care Teams – Help your patients find us and make a difference in research and care by sharing information about our program:

- Video: **About Community Voice** – video, 2 minutes (also available in **Spanish**)
- Flyer: **Community Voice: Be Heard, Make a Difference** – flyer (also available in **Spanish**)
- Projects: **Share Your Voice** – webpage with current and upcoming opportunities

Researchers – Contact us at CommunityVoice@cff.org to learn how we can help connect you with CF community insights.

Everyone – **Sign-up** for monthly updates to see the impact the CF community is having all year.

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