CELEBRATING 5 YEARS OF PARTNERING WITH THE CF COMMUNITY

Whether you’ve been a member for one year or for all five, thank you for sharing your stories, insights, and ideas. Without your partnership, these accomplishments would not have been possible. Cheers to the next five – and more!

ESTABLISHED IN DECEMBER 2014

2016: Members assisted in the development and launch of BreatheCon, CF Peer Connect, and the Clinical Trial Finder.

FIRST RESEARCH PRIORITIZATION PROJECT

2016: Members participated in one of the first research prioritization surveys, Insight CF, to help inform the Foundation’s work.

2017: CF care guidelines committees are now encouraged to increase community representation by inviting at least two adults with CF and one parent to serve on each committee.

2018: Members join the newly formed Spanish Language Community Review Committee to help make more resources available to the Spanish-speaking members of the CF community.

LAUNCH OF RESEARCH VOICE

2018: Research Voice members work to embed the voice of the community into CF research in a way that helps researchers improve study designs and address questions that matters most to the community.

2019: People with CF and family members now serve as community reviewers on the Clinical Research Committee to add insight on the feasibility and relevance of research proposals when making funding decisions.

2019: The framework for embedding the community in research is established.

CF FOUNDATION’S MISSION STATEMENT EXPANDS

2020: Aligning with the new five-year strategic plan, the Foundation’s mission statement expands to include partnering with the community - a critical component in the fight against cystic fibrosis.
2019 was a monumental year in CF research with the approval of Trikafta™, the triple-combination modulator therapy that works to treat the underlying cause of CF for those who have at least one copy of the F508del mutation. It was also a big year for the growth and impact that the CF community is having on research, as more researchers are partnering with Community Voice in meaningful ways. These partnerships are influencing what research is being prioritized and funded, shaping how studies are being designed, monitoring the safety of studies, and improving how research is communicated.

“Since 2014, Community Voice has raised awareness about the CF community’s needs and challenges to help us better direct research towards questions that will make the biggest impact. As we look forward to the next five years, we are committed to pursuing innovative ways to embed the voice of the community in all our work and improve the lives of everyone affected by CF.”

JP Clancy, MD, Vice President of Clinical Research

PRIORITIZING RESEARCH

Throughout 2019, members helped determine what research should be prioritized and funded. Eighteen Research Voice members served as community reviewers on the Clinical Research Committee to review clinical research grant proposals and provide feedback on each proposal’s feasibility and relevance to people with cystic fibrosis. Additionally, four community members were recruited to serve on a steering committee to help shape the priorities of the Foundation’s new Infection Research Initiative.
SHAPING RESEARCH

This year marked the first time that pharmaceutical companies sought input from Community Voice on their CF research programs. To help inform the early stages of Boehringer Ingelheim’s CF research program, several members participated in focus groups providing key insights to inform their work. Eight Research Voice members also served on an advisory group for an app-based study by Vertex Pharmaceuticals to understand the full burden of living with the disease.

Many members also contributed to studies conducted by academic investigators through committees, workshops, and focus groups. One example of meaningful input was the survey and focus groups that helped inform the design of STOP-Peds, a study focused on standardizing treatment for pulmonary exacerbations in children. Members helped the researchers understand the community’s interest on this topic, what questions needed to be answered, and how to improve the design of the trial to help parents feel more comfortable about their child’s participation.

"Community Voice members helped our research team understand why the topic of pulmonary exacerbations was important to the community and gave us critical insight on how to improve our study’s design to minimize participant burden."

DB Sanders, MD, MS, Co-PI of STOP-Peds Study

KEY AREAS OF FOCUS FOR 2020 - 2024

- Drive progress toward treating the underlying cause of CF for all people with the disease and delivering a cure
- Advance new and improved treatments to address the many manifestations of CF, including challenges associated with advanced disease
Community Voice members, along with others in the CF community, participated in the Care Center Survey to share insights about the relationships they have with their care teams and offer ideas on ways to address common challenges at CF care centers. Results from the survey indicated that not only does ensuring access to high quality care continue to be the top priority for people with CF and their family members, but addressing barriers to mental health services and insurance coverage are high priorities as well. These findings were used to help frame the ‘Care’ and ‘Community’ sections of the CF Foundation’s Five-Year Strategic Plan.

Members participated in additional care-related projects in 2019 by:
• Informing a decision-aid for women with CF on topics around reproductive health, pregnancy, and contraceptive choices
• Sharing their experiences on acquiring and using nebulizer compressors and nebulizer cups/kits to help address the challenges regarding equipment durability and accessibility
• Identifying Medicare coverage gaps for CF-related treatment and equipment
• Addressing the uses and perceptions surrounding complementary and alternative medicine to help inform an international study

“The perspective of those affected by cystic fibrosis is essential to designing effective approaches and evaluating outcomes. Since individual experiences vary widely, it is critical to involve a broad spectrum from the community.”

Gregory Smith, Community Voice member
Pictured with daughter, Leisha Cuddihy
INFORMING CARE LOCALLY

The results from the Care Center Survey and other related projects highlighted that many people in the CF community are partnering with their care team by participating in quality improvement projects and working together on Patient and Family Advisory Councils. While there has been progress in this space, we learned that there are still many valuable opportunities to help enhance these partnerships and promote collaborative care even more in the future.

INFORMING CF CLINICAL CARE GUIDELINES

Since 2015, Community Voice members have continued to influence the development of CF Clinical Care Guidelines. This year, members participated in two requests for public comment on the upcoming Palliative Care Guidelines and Advanced Lung Disease Guidelines. Three members also joined the newly formed Ear, Nose, and Throat Guidelines Committee to provide the lived experience perspective on the multi-disciplinary committee.

“Knowing we are helping to shape the future and guidelines for us and those to follow is empowering.”

Marcia Freeman, Community Voice member

KEY AREAS OF FOCUS FOR 2020 - 2024

- Support the best possible CF treatment and care delivery by generating high-quality data and evidence
- Evolve and support the CF care model and network to meet the future needs of people with CF across their lifespan, and ensure clinicians and researchers are equipped to meet the changing needs of people with CF
One of the most evident ways that Community Voice members helped support the CF community in 2019 was through the countless stories and experiences they have shared with others and the many resources they helped inform.

SUPPORTING ONE ANOTHER THROUGH SHARED EXPERIENCES

Members have continued to share their stories of living with cystic fibrosis to help inspire and support others who may be dealing with similar experiences. In 2019, there were:

- 46 members who served as facilitators for virtual event breakout sessions
- 5 adults with CF who were recruited to serve as facilitators for the new Teen Connections initiative
- 25 members who serve as peer mentors to help meet the needs of people requesting mentorship in the CF Peer Connect program

35 members shared their experiences with CF through 45 blog posts on the CF Community Blog about:
- mental health,
- lung transplantation,
- relationships,
- CFTR modulators,
- and much more.

"Sharing our voice empowers us to stay strong and help others in this fight. We have a life experience to share that will impact this fight in the most positive way. Being able to share what we’ve learned on our journey to help ease this path for others gives purpose to what we’ve been through."

Mary Pozsgai, Community Voice member
Pictured with son, Matthew Pozsgai
"I love seeing more and more adults with CF as an integral part of research, care, and how we handle challenges moving forward as a community. We are stronger together!"

- Marissa Benchea, Community Voice member

EMPOWERING THE CF COMMUNITY

In 2019, Community Voice members continued to play a critical role in the development of resources that empowered people with CF and their families to direct their health. The most comprehensive project members contributed to in 2019 was Navigating CF, an interactive series that was developed to help the community better understand insurance, financial, legal, and other topics related to life with CF. Community Voice members were consulted throughout the development process through a series of focus group and user testing exercises. Their feedback helped shape program design, content, user experience, and ongoing updates.

Members of the Spanish Language Community Review Committee were also hard at work as they helped review resources about Trikafta, Compass, and CF Peer Connect. Thanks to their work, not only did they help to ensure more Spanish-translated resources were available, but they also will help expand the reach of the Foundation’s programs and services that support the whole CF community in the future.

"Community Voice has been an extremely beneficial addition to the CF Foundation and CF community. I feel more informed than ever as to what is happening in the world of CF research and events. I appreciate the opportunity to get involved with projects, focus groups, surveys, webinars, and virtual events. It has truly helped connect the CF community!"

- Michelle Quintana, Community Voice member
Community Voice has been an integral part of the Foundation’s efforts to improve educational resources for the CF community. To inform tangible resources, members helped enhance the information available on cff.org surrounding substance misuse, gave valuable input on a handout about the purpose of placebos in clinical trials, and shared feedback on a guide for parents with CF to help teach their children about chronic illnesses.

Members were also involved in several aspects of this year’s North American Cystic Fibrosis Conference, an annual event where CF scientists, researchers, clinicians, and caregivers from around the world come together to discuss and share ideas on the latest advances of CF research, care, and drug development. They provided feedback on which conference sessions should be livestreamed, served as moderators for the event’s new chat feature to help guide community engagement and conversation, and participated in the post-event survey to provide valuable feedback on how to improve future conferences.

For the past five years, community members have helped center the Foundation’s research efforts around the community’s needs. Two members of Community Voice spoke on a panel to help share updates on the Foundation’s research portfolio and showcase how community input has helped drive improvements in recent CF research projects. Watch the webinar to learn more about some of the most recent work being done in this space.

**KEY AREAS OF FOCUS FOR 2020 - 2024**

- Support people with CF in living their best possible life no matter where they are on their CF journey
- Engage the CF community to shape Foundation programs to achieve our mission
- Expand the reach of programs and services to benefit more individuals across the CF community
ABOUT OUR MEMBERS

1,153 TOTAL MEMBERS

Over 85% of members participated in at least one project in 2019, with:

- 90 members serving on committees
- 96 members that participated in at least one focus group
- Over 650 members that completed at least one survey

To learn more about opportunities current members are excited about, check out the results from our end of year survey!

CONNECTION TO CYSTIC FIBROSIS*

Person with CF: 42%
Parent of a person with CF: 47%
Spouse of a person with CF: 4%
Other: 16%
(grandparents, siblings, children, aunts, uncles, in-laws, friends, etc.)

*Members may have multiple connections to CF.

Encourage others to join Community Voice!

We don’t know what’s important to the entire CF community unless we hear from everyone affected by CF. There are some groups in the CF Community who are less represented in Community Voice who we would like to hear more from.

If you know others in the CF community who identify as non-white or Hispanic, will not benefit from Trikafta, resides in the United States, are parents of a young child with CF, are teenagers living with CF, or who just want to get more involved and help shape CF programs and initiatives, please encourage them to join by visiting cff.org/CommunityVoice.
LOOKING AHEAD

"The CF community is a gold mine of information and it has been really gratifying to see the Foundation work hard to partner with us in so many ways over the last few years to gather our expertise."

Emma D’Agostino, Community Voice member

Thank you for being an essential partner in our shared mission to help provide all people with CF the opportunity to lead long, fulfilling lives. Looking ahead, we will continue to seek opportunities that push the boundaries of community engagement.

To align with the Foundation’s long-term focus on cure, care, and community, our priorities for 2020 include:

- Enhancing community engagement in CF research and care
- Exploring the community’s perspective of living with CF since the approval of Trikafta
- Expanding the reach of Community Voice to better include underrepresented populations in the CF community