2018 Year in Review
2018 Demographics

913 members in Community Voice now represent all 50 states in the United States. Nine are international members.

Community Voice has grown 13 percent in membership since 2017 with the addition of 103 new members.

**CONNECTION TO CYSTIC FIBROSIS**

Person with CF: 41%
Parent of a person with CF: 50%
Spouse of a person with CF: 4%
Other: 13%
(grandparents, siblings, children, aunts, uncles, in-laws, friends, etc.)

*Members may have multiple connections to CF.*

Members Across the Nation

Number of Community Voice Members:

- 0
- 1-9
- 10-19
- 20-29
- 30-39
- 40-49
- 50+
In 2018, Community Voice members were hard at work making their voices heard across the Cystic Fibrosis Foundation and beyond. From surveys to focus groups, committees, and other opportunities, it’s clear how dedicated members are to improving the lives of everyone affected by cystic fibrosis.

Opportunities sent to Community Voice members are tailored based on your interests and skill sets. If you would like to review and update your profile, please contact us at communityvoice@cff.org.

The Collective Power of the CF Community

By spending just five minutes to complete quick and easy surveys, Community Voice members amplified their efforts to influence several initiatives in 2018.

- **5 minutes**
  - average time members spent completing a survey

- **30 opportunities**
  - average number each member received

- **3,500+ responses**
  - total survey responses submitted in 2018

What it means to have the community involved in the Foundation’s work

“My involvement with Community Voice has broadened my appreciation for the people with CF and the larger community and the struggles and the challenges they all have. I joined about two years ago with no expectations, and the impact that it has had on me personally is immeasurable.”

**Carl Riedy, Community Voice Member**

“Community Voice makes me feel powerful, it makes me feel like I have a voice for the first time in a long time. I’m a part of something more that’s going to make a difference for everybody.”

**Marieliz Landa, Community Voice Member**
One of the most powerful examples of how Community Voice has prioritized, shaped, and influenced the work of the CF Foundation is the expanded focus on CF-related infections.

**Informing the need**
The community’s influence began with a project that was conducted at the beginning of 2017. Community members submitted questions that they wanted researched by the CF Foundation. Members then voted on what research topics should be prioritized, and infections by far was ranked as the most important priority area for clinical research.

**Prioritizing the needs**
While the CF Foundation has always supported research on treating infections, the overwhelming feedback from the community helped identify the need for additional infection research and played a pivotal role in the decision to create the Infection Research Initiative. Following this prioritization activity, the Clinical Research Advisory Board asked Community Voice, alongside CF researchers and clinicians, to do another prioritization survey that went into more detail on different categories, including different areas on preventing and treating CF-related infections.

**Shaping the work**
As the Infection Research Initiative began to take form, members of Community Voice participated in focus groups to inform and clarify the areas the initiative needed to focus on and how to best convey the information to the community.

**Steering the work**
This incredible story of how the community, researchers, and CF Foundation staff helped shape a $100 million initiative is just getting started. In 2019, the Infection Research Initiative Steering Committee will form including members of Community Voice to help inform the work of this initiative.

---

"Community Voice provided critical insight into the community’s concerns and was instrumental in informing the development of the Infection Research Initiative.”

Ann Field, Senior Director
Drug Discovery & Development

---

Community Voice members also helped plan and pick topics for the first-ever ResearchCon on Feb. 28, 2019, a virtual event by and for the CF community dedicated to cystic fibrosis science and research around infections.
Community Voice members influenced over 70 initiatives across the CF Foundation, including areas such as CF research, CF care, community support, and storytelling.

Within the CF research space, the number of opportunities for members to participate increased significantly since 2017, and ranged from survey opportunities to committee membership. Community member inclusion in this type of work helped the CF research community learn more about the needs and preferences of patients and caregivers. This partnership helped focus researchers on the topics most important to the community, reduce barriers to participating in studies, and expedite the clinical trial process.

**CF Study Design**

Community Voice has also driven research forward by identifying priority areas for grant funding, through prioritization surveys, and through a recent survey which highlighted what the barriers are to participating in clinical trials. By partnering with CF researchers in study design, the CF community has helped identify solutions to make it easier for community participation.

Below are two examples of how specific studies are using Community Voice to inform the design of studies.

**GI Wellness Study**
By reviewing and voting on which questionnaire best reflected outcomes the community cares about, Community Voice helped choose the outcome measure that will be used in future GI studies, ensuring that researchers are studying what matters most to the community.

**Treatment Simplification Study**
The CF community prioritized “reducing treatment burden” as a top priority area for research and gave feedback on what would make the biggest difference when designing a study to reduce therapies. This study is currently being developed and is incorporating the feedback from the community.

“Treatment simplification in the context of highly effective modulators in an extremely important yet complex idea. It was essential and highly enlightening to receive direct feedback via a focus group and survey responses from the CF Community on what is important to them and what a potential clinical trial should focus on.”

Kelsie Pearson, TDN Coordinating Center
Want to get more involved with CF research projects?

Research Voice is a sub-group of Community Voice that was created to embed the voice of the community specifically into CF Foundation-sponsored research projects. To learn more, visit cff.org/CommunityVoice today!
When a guidelines committee is convened, they recruit CF community members through Community Voice to ensure the community’s perspective is represented on multi-disciplinary committees.

Serving on various committees

When a guidelines committee is convened, they recruit CF community members through Community Voice to ensure the community’s perspective is represented on multi-disciplinary committees.

Active committees focused on clinical care guidelines:
- Advanced Lung Disease Guidelines Committee
- Palliative Care Guidelines Committee
- Post-Transplant Guidelines Committee
- Transplant Referral Consensus Guidelines Focus Group

Informing the scope of upcoming guidelines

Often in the early stages of the development of new clinical care guidelines, members of Community Voice share what is most important to them. In 2018, community members shared their experiences with ear, nose, and throat (ENT) referrals and treatment, and gave input on what is important for the new committee to address in guidelines development.

Reviewing of draft summaries and recent publications

Once a draft guideline is developed, it is sent out through Community Voice and other channels for public comment, which gives both the patient and clinical communities a chance to weigh in on the draft guidelines before they’re shared on the CF Foundation website. Members of Community Voice give input on this web content through surveys and focus groups. In 2018 members weighed in on the Lung Transplant Referral Guidelines for People With CF, as well as the CF Colorectal Cancer Screening Clinical Care Guidelines and its informational content on cff.org.

“I feel like a true partner and colleague on the Palliative Care Guidelines Committee, and it’s empowering contributing to an initiative that we hope will help ease the physical and emotional burden that the community faces. My experiences are respected and heard -- I’m not a bystander to decisions that could impact my care. I get to help shape them!”

Cade Hovater, Community Voice Member

“Patient and family community members contribute to the development of guidelines by sharing their lived experiences. They bring their own preferences about how their care is conducted and opinions about the benefits and harms of treatments, therapies, and practice that might not otherwise be found in the committee’s review of the literature.”

Sarah Hempstead, Clinical Affairs Department
“Community Voice is important because it’s more than just new research that people with CF need from the CF Foundation. It’s a lifetime of support, education, and research opportunities that are really patient-directed and it’s been a really good way for me to have some input in that process and say ‘This is what I really need as a community member.’”

James Lawlor, Community Voice Member

Other Care Projects in 2018

Care Experiences
Members of Community Voice are helping to improve the experiences at their CF clinic by giving input on and refining the Patient Experience of Care survey, and by sharing specific experiences with their center’s patient and family advisory councils. This feedback will help give insight into needed resources for these groups.

Pain Management
In an effort to learn more about pain management in the CF community, researchers at Johns Hopkins University gathered insights from Community Voice and other CF community members about their experiences with pain.

The community’s input on this topic showed that providers vastly underestimate the percentage of people with CF who experience pain. These findings will now be used to advocate for more education and CF-specific pain management guidelines for CF clinicians and researchers.

CF Care Commitee

Education Commitee
Community Voice members serve on this multi-disciplinary committee in order to improve access to CF educational material for patients, families, health care providers, Foundation staff, and other volunteers.

““The impact that you can have on the quality of CF care and the work of the Foundation is real. Your voice matters.”

Chris Kvam, Community Voice Member
Impact Areas • Community Support

Thanks to the input and involvement of Community Voice, there are now more efforts underway to support the CF community in navigating life with CF than ever before. Members have also taken a more active role in supporting the community by:

• Planning and facilitating virtual events including the first ever CF FamilyCon, BreatheCon, and four CF MiniCons.
• Serving as mentors for the newly-expanded CF Peer Connect program, which is now open to family members in addition to adults with cystic fibrosis.
• Shaping educational resources for people with CF, caregivers, and Spanish-speakers on topics such as mental health, placebo use in clinical trials, and communicating with care teams.

“\’I’m not only a part of Community Voice, but my adult daughter is as well. Both our perspectives are important to the conversation. Her experience with CF is different than mine and more of a reason for our voices to be heard through Community Voice.\’”

Jennifer Bleecher, Community Voice Member

Impact Areas • Storytelling

Every CF story is different, but each story can help someone going through something similar feel less alone. What makes Community Voice so powerful is the opportunity it gives members to share their unique stories and perspective on a wide variety of topics.

Substance Misuse

One important project where Community Voice members shared their stories was during a focus group on substance misuse. This helped inform how the CF Foundation communicates about this important topic and how we can best normalize discussion about it in the clinical setting. Participant Marieliz Landa went on to contribute a blog post to the CF Community Blog about her personal experience on the topic -- which was one of the top 10 most-read posts in 2018!

Like Marieliz, 77
Community Voice members have also shared their experiences of living with cystic fibrosis in over 150 posts on the CF Community Blog on topics such as relationships, emotional wellness, adult care, lung transplantation, and more.
Looking Ahead

“To be involved in Community Voice means a lot to me. There is only so much that researchers and care teams can do. It’s the experiences of those living with CF who can also give valuable information, and to know that our voices are being considered means that they care about us beyond just moving research. They really want to know what is going to benefit us the most.”

Aimee Lecointre, Community Voice Member

Reflecting on 2018, we celebrate the huge accomplishments that Community Voice members have contributed to this past year. Looking forward to 2019, we will continue our unrelenting commitment to find innovative ways to embed the voice of the CF community into everything the Foundation does. Thanks to thoughtful feedback from the end-of-year survey, we have also developed the following priorities that align with this commitment.

Our 2019 priorities include:

1. Experimenting with new methods to effectively communicate information, including a monthly digest email where members can track the status of different projects.

2. Exploring new ways to get involved in various aspects of the research space including training CF researchers on the value of including the community in the design of CF studies.

3. Finding innovative strategies to reach new audiences and diversify the representation of members within Community Voice, including creating videos that can be shared about why it is important to share your voice.