



Frequently Asked Questions

What is Community Voice?

It is your chance to use your voice, be heard, and make a difference.

People living with cystic fibrosis and their families know CF better than anyone, and Community Voice is an empowering volunteer opportunity for you to share your experiences, perspectives, and knowledge. As a member you can make an impact that benefits the entire CF community by bringing your insights and priorities to the forefront of CF research, care, and programs.

Why is Community Voice important to the CF Foundation?

The input of the CF community helps ensure our success in improving the lives of ALL people with CF, and Community Voice is the avenue for getting that input. Established in 2014, this go-to group shares their experiences, opinions, and unique perspectives, which are vital to the success of research, care, and programs at the Foundation and beyond.

Who should join?

People living with CF and their family members, who are ages 13 and older, including:

- Adults/Teenagers with CF
- Parents
- Siblings
- Spouses/Partners

Each person's experience is unique, so it is critical to hear from as many people as possible. As we strive to best represent our entire CF community, it is especially important to hear from community members who do not benefit from highly effective modulator treatments, who have experience with transplantation, who identify as male, who are people of color, and who are parents of young people living with CF.

Why should someone join?

- To take an active role in shaping and improving the future for the entire CF community
- To provide input on topics that are meaningful to you
- To share your unique perspective and experiences to drive change
- To receive exclusive updates and a behind the scenes look at CF Foundation initiatives and research

What does participation look like?

As a member, customized opportunities to participate will be emailed to you based on your interests. You can share your opinions through 5-minute surveys, and you might have the opportunity to apply to be part of focus groups or serve on committees.

How much time does it take to be a member?

Being a Community Voice member is a no-pressure way to get involved. You choose how much -- or how little -- you want to participate on the topics that are of the most interest to you. All opportunities are optional, and you can expect about 2-4 per month. However, you can choose your level of participation based on your schedule and interests. On average, most surveys will take just 4-6 minutes to complete and there are other projects and priorities that will require more time, such as focus groups, committees, working groups, and speaking opportunities. At the top of each email, we always let users know about how long each project takes to complete. No matter your level of participation, you are making a difference!

Do I need any special skills or knowledge to be a member?

You know CF better than anyone else – your lived experience is all you need!

What types of projects will I be part of?

It is the goal of the Foundation to embed the voice of the community in all that we do. This means that you will have the opportunity to share your insights on a variety of topics that are meaningful to you, including: innovations in CF care, public policy and advocacy, drug development and research, programs for people with CF and their families, and many more! Check out the [Monthly Results Update](#) to learn more about past projects.

Will I be invited to participate in every opportunity through Community Voice?

We use the profile information that you provide when you sign up to be a part of this group to customize the types of requests that are sent to you, so that they are most relevant to your interests and experiences. You can easily update your interests by creating or logging in to your profile at my.cff.org/CommunityVoiceSignup.

What can I look forward to as a member of Community Voice?

At the end of each month, a [Monthly Results Update](#) email is sent out to members of Community Voice. In these digests you can learn about the recent opportunities that members have participated in; the feedback, ideas, and insights gathered; and the next steps or impact of each project. You will be able to see how participation in Community Voice is impacting the CF community while gaining an insider's perspective on Foundation research, programs, and care initiatives.

I signed up but I do not remember what I included on my profile. Can I view it?

If you signed up through my.cff.org/CommunityVoiceSignup, you can log in to view your profile at any time. If you have not created a profile, please contact communityvoice@cff.org for assistance.

My information has changed. Can I update my profile?

Absolutely! Whether it is updating your contact information, skills, interests, or availability, you can log into my.cff.org/CommunityVoiceSignup to update your information at any time or email communityvoice@cff.org for assistance.

How do I join?

Visit my.cff.org/CommunityVoiceSignup to join today. You will be asked to tell us more about you and your interests so we can personalize emails to highlight opportunities that matter the most to you.

What if I have additional questions?

Email communityvoice@cff.org at any time, and we will be happy to answer any additional questions.

What if I no longer want to be a part of Community Voice?

If you would like to opt out of Community Voice, please email us at communityvoice@cff.org.