Dear Community Voice members,

Looking back on 2017, it is astonishing to see how many of you pledged your time and commitment to make a difference in the cystic fibrosis community. Not only have we seen a huge growth in the number of Community Voice members, but in the number of projects you all have contributed to as well.

In the past year, we changed our name from the Adult and Family Advisors to Community Voice, a name chosen by you. You picked this name because it embodies exactly what the purpose of this group is: a place to amplify your voice to improve the work being done for the CF community. Whether you’ve taken a survey, participated in a focus group, or joined a committee, your voice has led to a culture shift both within and beyond the Foundation.

Thanks to your thoughtful feedback and contributions as a Community Voice member, clinicians and researchers are increasingly eager to reach out to the community for input on designing new projects, studies, and resources. At the Foundation, you have influenced key decisions about which research projects to fund, what content topics to address on cff.org, which new initiatives can help to confront the distinct challenges facing adults with CF, and so much more.

As we look forward to 2018, we hope you know that every call you participate in or survey you take has an impact and brings us one step closer toward curing cystic fibrosis and providing all people with the disease the opportunity to lead full, productive lives. Your voice guides the Foundation and many others on this path.

Thank you for all you do for the CF community!

The Community Voice Team
810 TOTAL MEMBERS
143% growth since 2016 (334 to 810)

CONNECTION TO CF*
- Person with CF: 38%
- Parent of a Person with CF: 50%
- Spouse of a Person with CF: 3%
- Other: 14%
  (grandparents, siblings, children, aunts, uncles, in-laws, friends, deceased, etc.)

*Members may have multiple connections to CF

MEDIAN AGE RANGE OF ADULTS WITH CF IN COMMUNITY VOICE:
26–33 YEARS OLD

MEDIAN AGE RANGE OF FAMILY MEMBERS IN COMMUNITY VOICE:
45+ YEARS OLD

68% OF COMMUNITY VOICE MEMBERS ARE FEMALE
(27% are male, 5% prefer not to say)

Members Across the Nation
Member Engagement

In 2017, Community Voice continued to identify new ways for members to come together and lend their voices to make a difference in the CF community. According to the 2017 end-of-year survey, members were involved in more projects and initiatives than ever before.

- **69 OPPORTUNITIES**
  - Sent to members this year

- **130 EMAILS**
  - Sent to Community Voice members

- **5 MINUTES**
  - Average time spent completing a survey

- **4 (OUT OF 5)**
  - Average rating of member’s experience with Community Voice

- **24%**
  - Want to further engage in focus group/interview opportunities

- **50%**
  - Members strongly recommend Community Voice

What do members like most about Community Voice?

- “The fact that I feel informed on important matters affecting my children.”
  
  Anne

- “I love the diversity of participation options offered!”
  
  Xan

- “The ability to share my experiences and opinions and seeing that information making a difference.”
  
  Aimee

- “The opportunity to participate on your own time.”
  
  James

- “That I have a voice and that my voice matters.”
  
  Nicole
Impact Areas

Community Voice members were also able to get involved in a greater variety of topic areas across the Foundation and use new channels to make their voices heard. In 2017, members participated in nearly 70 opportunities, including:

### Improving CF Care and Research

Community Voice had an enormous impact on improving CF care and research this year on a range of topics and projects including:
- Ways to improve palliative care
- Improving communication between care teams and CF patients
- Clinical care guidelines
- Helping to understand the needs of CF caregivers
- Addressing taboo topics, such as hemoptysis (coughing up blood)
- Identifying key research priorities from the Patient Registry, which can then be applied to the research being done in clinics

### Community Support

Thanks to your input and involvement, there are now more programs to support the CF community in navigating life with CF than ever before. By working with the Foundation to create and shape these programs, Community Voice members helped:
- Inform the design and promotion of CF Peer Connect, a program that connects adults with CF to peer mentors
- Plan, facilitate, or participate in virtual events including BreatheCon and two CF MiniCon events on transplant and young adult transitions
- Volunteer for 2018 virtual events that will include CF family members
Impact Areas

Transplantation
Community Voice members have helped contribute to our new transplant initiative in multiple ways. We have had members join committees, share how they engage with their social networks to talk about transplant, discuss their ideas for how the transplant process could be improved, and even contribute pictures that were shared at the 2017 North American Cystic Fibrosis Conference to illustrate the importance of transplant for the CF community.

Advocacy
We know many Community Voice members made phone calls, sent emails, and met with their elected representatives to advocate for adequate, affordable, and accessible health care coverage this year. Several members also participated in interviews and focus groups for a survey to support health care insurance access.

Storytelling
One of the most visible ways that Community Voice has made an impact this year is through all of the stories members have shared through the CF Community Blog, speaking engagements, surveys, focus groups, and other projects.

“"I like that individuals can share their experience since CF affects everyone so differently."" 
Jillian, Community Voice member

Education
In 2017, many Community Voice members also helped improve educational resources to ensure that all people with CF have access to high-quality information on managing their disease. This year, you made it easier for the community to find the answers they need by providing your feedback on:

- The new Trailblazer campaign to help educate and connect people to clinical trials
- A new infographic explaining the different cystic fibrosis transmembrane conductance regulator (CFTR) mutations
- A revamped research section on cff.org to improve transparency of Foundation-funded research initiatives
- The Adult Guide, a resource for adults with CF to help manage life with the disease
- New messaging about the CF Model of Care
Committee Membership

One way that Community Voice members can influence initiatives at the Cystic Fibrosis Foundation is by serving on committees. In joining a committee, community members work closely with experts in the field and dedicate several hours of their time and energy to ensure that the CF community is represented on multidisciplinary teams. Committee members work hard behind the scenes to implement programs and identify new ways to improve care and life with CF. The inclusion of CF community members in these groups has proven to be incredibly beneficial to the innovation and implementation of many initiatives.

Below is an overview of the many Foundation committees where Community Voice members are involved:

Clinical Care

**Mental Health Advisory Committee**
Addresses the importance of mental health among people with CF and their families by focusing on three areas: education and training, collaboration and consultation, and research.

**Palliative Care Guidelines Committee**
Develops clinical care guidelines outlining recommendations for incorporating palliative care into the CF care model.

**Success with Therapies Research Consortium (STRC) Committee**
Identifies, tests, and designs behavioral interventions that improve sustained daily care and CF disease self-management while also improving health outcomes and quality of life.

Partnerships for Sustaining Daily Care (PSDC) Champions Committee
Spreads information about partnerships between people with CF and their care teams, brainstorming ideas on outreach, and providing feedback on programmatic efforts.

**PSDC Communication Steering Committee**
Leads an exploratory effort to better understand the communication needs and preferences of individuals with CF, their families, and their CF care teams.

**CF and Reproductive Health Task Force**
Develops new resources surrounding key sexual and reproductive health topics for girls and women with cystic fibrosis.

Transplant Initiatives

**Advanced Lung Disease Guidelines Committee**
Focuses on understanding the needs of people with CF who have advanced lung disease as well as the care centers and transplant centers that treat them in order to develop lung disease guidelines as well as resources and tools for CF community members and care providers.

**Transplant Referral Best Practices Committee**
Focuses on understanding the transplant process and communication practices between CF centers and lung transplant centers, and is charged with developing tools for CF community members and care providers.
Committee Membership

Community Engagement

**CF Community Blog Editorial Board**
Ensures that the [CF Community Blog](#) offers a safe space for people to connect and learn from one another through the sharing of experiences, reflections, and stories from across the CF community.

**Community Voice Newsletter Editorial Board**
Helps to inform and review content for the new Community Voice newsletter which highlights past Community Voice projects, new opportunities, and member insights.

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**WHAT IT MEANS TO HAVE THE COMMUNITY INVOLVED IN CFF’S WORK**

“Having real people respond to our content before it goes live is absolutely essential to producing a valuable resource for people with CF. Their feedback provided important insight into our project.”

*Susan, CFF Communications*

“The value of community input in our research cannot be stated enough. Community members give the best feedback so we can design studies that will make the greatest positive impact on the most patients.”

*Sarah, CFF Clinical Affairs*

“Knowing we have access to the perspectives of the very people we are committed to helping not only saves us from our own biases and assumptions, but also reminds us to be respectful of the agency and expertise that people with CF and their families have.”

*Quynh, CFF Communications*

“It’s so important to have a direct line to hear straight from the community on programs and services the CFF is putting together. The Partnerships for Sustaining Daily Care program couldn’t exist without members of the community and the feedback from Community Voice.”

*Katherine, CFF Clinical Affairs*
Launched in summer 2017, Research Voice is a sub-group of Community Voice designed for members who want to get involved in CF research on a deeper level. Research Voice members undergo a special training to better equip them to serve on different research initiatives. So far, we’ve seen members get involved in several projects across each stage of the clinical trial process, from helping to set research priorities, to reviewing studies for safety and ethics, to disseminating study results to the public.

Research Voice will only continue to grow in its impact in 2018. We are excited to begin a partnership with the **Therapeutics Development Network** to bring insights from Research Voice directly to pharmaceutical companies early in the planning process so that the CF community has input into how studies are designed. Through this and other upcoming projects, we are committed to expanding opportunities for Research Voice members to ensure that the voice of the community is included throughout the research process.

If you would like to join Research Voice, please fill out [this survey](#)!

**Research Impact:**
In 2017, Community Voice and Research Voice members had a major impact on research prioritization by participating in a detailed survey to identify gaps in our current research agenda. Their [feedback](#), which was presented to the Clinical Research Advisory Board by a committee member from Research Voice, was used to help inform priority areas for 2018.

The diagram below shows each phase of a clinical research study on the right, and the committees where members are making an impact on the right.

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**Community Involvement Throughout the Clinical Study Process**

- **Protocol Design & Review**: Protocol Review Committee (**PRC**) reviews clinical research study protocols before a study.
- **Site Selection & IRB Approval**: Shullman Institutional Review Board (**IRB**) reviews and approves study protocols and materials to ensure a study is ethical and that participants are protected.
- **Patient Participation**: Data Safety Monitoring Board (**DSMB**) monitors and protects the safety and welfare of people enrolled in clinical trials approved by Cystic Fibrosis Foundation Therapeutics Inc.
- **Begin Enrollment**
- **Study Closes**
- **Data Analysis**
- **Publish Results**: Research Summary Review Committee reviews lay summaries of completed studies to ensure they convey the key points in a clear and understandable manner.
Looking Ahead

There is no doubt that 2018 is going to be another big year. In January alone, Community Voice has contributed to two new major advocacy initiatives, helped to improve plans to assist the CF community when natural disasters happen, weighed in on clinical research priorities for 2018, and signed up to get more involved in virtual events.

As we move into 2018, we want to ensure that each Community Voice member’s experience is as fulfilling as possible. We are committed to finding innovative ways to embed the community’s voice into everything the Foundation does and will continue to better communicate the influence the community is having through the Community Voice newsletter.

Thanks to Community Voice members’ thoughtful and honest feedback from the end-of-year survey, we were able to develop yearly goals that will help make the Community Voice group even better in 2018!

This year we will be focusing on:

1. Improving member engagement, including sharing results more frequently
2. Increasing the number of opportunities to get involved, particularly in the research space
3. Finding innovative ways to expand the reach of community feedback and apply it to new topics and programs across the Foundation

Please do not hesitate to email us at communityvoice@cff.org if you want more information on a project or have ideas about how we can continue to improve Community Voice.

We’d like to hear your thoughts! Email us at communityvoice@cff.org.

Together we can do more. Invite others to join Community Voice today.

Didn’t get to read the Community Voice Newsletter? Read all about it here!

“\A big thank you to those who responded to survey and interview requests, it's amazing how engaged the CF community is – we would not be able to do the work we do without their input and guidance.”

Jackie, CFF Policy and Advocacy