Since 2014, Community Voice’s mission has been to empower and provide opportunities for everyone affected by cystic fibrosis (CF) to actively impact research, care, and programs for the CF community. Year after year, you continue to drive forward progress for the CF Community.

Over the past year, the impact members of Community Voice made was seen more than ever before, including:

- Five sessions and nine **abstracts** at the North American Cystic Fibrosis Conference (NACFC) showcasing how prominent a role the community is playing in research and care advances. This included studies like SIMPLIFY and STOP Peds, which members helped design several years ago, which are now publishing results that will have a direct impact on treatment decisions.
- The Wellness in the Modulator Era (Well-ME) survey, which was co-designed by Community Voice members and is the most comprehensive look into the overall impact modulators have had across the whole person including mental, physical, social, and financial wellbeing.
- Several projects focused on understanding and working toward eliminating health disparities within the CF Community.

Community Voice members sharing their perspectives and partnering with us is critical to the mission of the Cystic Fibrosis Foundation. They keep researchers, clinicians, and CF Foundation staff connected to the ongoing challenges the CF community face and are our partner in driving meaningful progress.

We are excited to see what lies ahead in 2023. Several impactful projects on are the horizon, including topics like genetic therapies, financial wellness, improving access to clinical trial information, understanding priorities in reducing treatment burden, mental health and many more.

With gratitude,

**Christina Román**  
**Director, Community Insights and Partnering**
THE COLLECTIVE POWER OF COMMUNITY VOICE

85% of Community Voice members engaged in some way in 2022*:

- 600+ Members participated in high-impact projects that involved extensive engagement
- 400+ members completed at least one survey, with over 2,900+ total survey responses submitted from across the CF community
- 134 members served across 30 national committees/workgroups
  - 14 recruitments that added 43 members in 2022 alone

Community Voice members participated in more than 60 opportunities:

- 19 projects focused on enhancing the design of CF research studies
- 13 projects on improving CF education and resources for the community
- 5 projects focused on wellbeing or wellness
- 5 projects focused on health equity

*Based on email engagement; count may be inflated due to Apple’s Mail Privacy Protection feature.
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:

- Identify as male
- Identify as a person of color
- Identify as Hispanic/Latinx

If you know others who want to get more involved and help shape research, care, and programs, please encourage them to join by visiting cff.org/CommunityVoice.
MAINTAINING THE MOMENTUM
PROGRESS IN RESEARCH & CARE

TOPIC SPOTLIGHT: FOCUSING ON HEALTH EQUITY

The CF Foundation’s commitment to Equity, Racial Justice, Diversity, and Inclusion has helped the Foundation better understand the wide health disparities impacting the CF community. This commitment provided an opportunity for members to support many projects focused on reducing disparities in the CF community.

**Newborn Screening Steering Committee:** Supports the Foundation’s larger newborn screening initiative to improve sensitivity, timeliness, and equity in diagnosing babies with CF.

**When we received my son’s CF diagnosis after a false negative newborn screen, I felt compelled to share our experience within this space.**

Community Voice provided me the opportunity to apply for the Newborn Screening Steering Committee where it has been incredibly meaningful to meet with experts monthly to contribute toward this goal and truly feel like my voice is being heard.

Cambrey White, Community Voice Member

Highlighting the unique experiences of groups within the CF community: The Communities of Color Report, which affirmed that race often affects every aspect of an individual’s experience with CF, was shared across 4 sessions at NACFC. A focus group by the Partnership Enhancement Program (PEP), built on this work, to explore how to build and maintain trust between care teams and patients.

**Research to advance health equity:** Focus groups and a workshop were held to identify gaps in knowledge and research priorities including improving the understanding of things like:

- Cost and impacts of cost.
- Access challenges for the CF community.
- How to screen for social risk factors and successfully intervene to reduce disparities.

These findings informed the development of the CF Foundation’s Health Equity Team Science Award - a new funding opportunity for researchers to advance in health equity in the CF population.

Hearing from community members with cost and other challenges such as food, housing, and transportation helped the Foundation prioritize research that will help us understand and reduce the impact of these needs.

Thank you for your honesty and valuable feedback. I’m thrilled to see your perspectives incorporated into projects such as the Health Equity Team Science Award.

Olivia Dieni, Senior Specialist, Health System Innovation & Navigation
INFORMING THERAPEUTIC DEVELOPMENT

Community involvement in therapeutic development is critical as it improves the impact and feasibility of studies and ensures that researchers are guided by the experiences of those living with CF.

Genetic therapies: Focus groups were hosted to inform the creation of an infographic to improve understanding behind genetic therapies. Members of the Genetic Therapies working group also created a community-facing glossary of genetic therapies terms and a resource focused on questions to ask your care team about genetic therapy trials. Members also participated in a survey conducted by Emily’s Entourage to inform genetic therapy research, which was shared at NACFC.

Drug Development: Pharmaceutical companies continue to incorporate the CF community’s perspective in various areas of clinical research like trial design and future drug development via projects such as:

- Interviews focused on the experiences of people with CF with pseudomonas, assessing how to ease the burden of tests/evaluations required for trial participation such as the importance of at-home testing/sample collection, shorter wait time at the hospital and care centers, as well as more financial assistance with travel and meals while participating in clinical trials.
- A survey on pancreatic enzyme replacement therapy (PERT) which demonstrated the continued interest and willingness to participate in prospective research studies on PERT. This information will be used to shape upcoming work around a potential new therapy.

For the first time ever, the Clinical Research Executive Committee (CREC) recruited an adult with CF in Community Voice to serve as a stakeholder amongst CF Foundation and Therapeutics Development Network (TDN) leadership. This member is providing scientific leadership to the CF Foundation’s TDN by helping establish priorities, evaluating and rating scientific protocols, reviewing the network’s activities, and determining which studies should be sanctioned for the network.

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**I JOINED THE CREC HOPEING TO USE MY BACKGROUND IN AND PASSION FOR CF RESEARCH TO PROVIDE A VOICE OF THE PATIENT COMMUNITY. I CONSIDER THIS ROLE TO BE ONE OF MY GREATEST PRIVILEGES AND RESPONSIBILITIES IN MY LIFE AND AIM TO STRENGTHEN THE WAY THERAPEUTICS ARE DEVELOPED WITH EVERY PATIENT IN MIND FROM THE VERY BEGINNING.**

**Tré LaRosa,**
Community Voice Member

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**I CANNOT BELIEVE IT TOOK SO LONG TO HAVE A COMMUNITY MEMBER ON THE TDN CREC AND NOW I’M IMAGINE THE COMMITTEE HAVING DISCUSSIONS AND MAKING DECISIONS ABOUT OUR RESEARCH WITHOUT A COMMUNITY MEMBER’S VOICE AND VOTE. THEIR INPUT, EXPERIENCE AND PERSPECTIVES ARE INVALUABLE TO OUR MISSION.**

**George Retsch-Bogart,**
MD,
Chair, Cystic Fibrosis Therapeutics Development Network Clinical Research Executive Committee
As care for people with CF evolves, keeping the community’s perspective at the center of research remains a priority; and partnering with clinicians and researchers has shown to be an impactful way to improve CF research and care outcomes.

**IMPROVING CF CARE THROUGH RESEARCH**

Treating pulmonary exacerbations: Feedback from focus groups informed the design of the STOP-360 study which assesses use of at-home treatment of pulmonary exacerbations vs. hospitalization.

**OPTIMIZING TREATMENT IN INNOVATIVE WAYS**

- **LITE Study Review Team**: This expert review panel supported research study development of the Multiple Breath Washout (MBW) test and contemplated if this test can inform treatment decisions among CF care providers.

- **Community Grant Reviewers**: Community members review grant proposals and their input on the proposal’s feasibility and relevance to people with CF which is incorporated into the overall funding decision as well as provided feedback to grant applicants to improve their studies.

In addition to the clinical research grants community members also weighed in on Remote Tools for CF Care Delivery proposals to evolve remote care options. These applications specifically looked tools, tests, processes, and practical considerations for gathering clinical data outside of in-person clinic visits.

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**We were so impressed with the number of Community Voice members who joined our focus groups to give us feedback on our pilot study looking at treating pulmonary exacerbations at home more effectively – and even more WOWed in the ideas and opinions they shared. The feedback was invaluable, as they gave us novel ideas we had not thought of! The ability for CF researchers to quickly make sure that potential studies meet patients’ needs is critical. Thank you to all members for being so gracious with your time!**

Natalie West, Assistant Professor of Medicine, John Hopkins University Pulmonary and Critical Care Medicine

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**Further Reading:**

Learn more about research the CF Foundation funds.
RESEARCH AGENDAS

Working group and committee involvement allows members to partner with clinicians and researchers and share their lived experiences to develop research questions and support protocol design. Below are some of the research work groups and committees that Community Voice members participated in:

- **Success with Therapies Research Consortium (STRC):** Steering committee members provide feedback to STRC investigators about interventions, protocols, and study conduct. The Steering committee also makes decisions about the overall operation and policies of the STRC.
- **Reflux Workshop Series:** This five-part virtual workshop series was designed to bring clinicians and community members together to discuss how to improve identification, diagnosis, and treatment of reflux in people with CF at various stages of their medical journey.

I was very pleased to participate in the Reflux Workshop Series to provide the CF post-transplant patient perspective. The topic we discussed and the workshop series was cutting edge, in an area that affects many post-transplant CF patients. Looking forward to additional research happening as a result of this series.

  - **Laurel Avery,** Community Voice member

- **Sexual and Reproductive Health:** The Women’s Health Research working group was expanded to include the health concerns of men, women, and the LGBTQIA+ community. Within this work, a subgroup that consists of clinicians, researchers, and four Community Voice members will also focus on identifying the gaps in knowledge around sexual health, gender, and reproduction issues that impact men with CF.

  Hearing from Community Voice helped us design a study of pregnancy in CF to understand people’s concerns and the questions they have on this topic.

  As the SHARING and men’s health research working groups design future studies to understand and improve sexual and reproductive health for people with CF, we are excited to partner with Community Voice to ensure that we are addressing relevant topics that will make a difference in people’s lives.

  - **Raksha Jain,** M.D., M.Sc., ATSF
    Professor of Medicine, Pulmonary and Critical Care Medicine
    Director, Adult Cystic Fibrosis and Bronchiectasis Program
    University of Texas Southwestern Medical Center
Dramatic changes in the CF Community resulting from modulator medications prompted a deeper dive into how modulators are impacting overall wellness including quality of life, mental and physical health, and financial and social wellbeing. A multi-disciplinary team of four community members, care team members, CF Foundation staff, and researchers from The Dartmouth Institute of Health Policy & Clinical Practice developed the Wellness in the Modulator Era (Well-ME) survey to assess the holistic impact of modulators.

More than 1,000 community members shed light on the diverse experiences of life with CF after the approval of CFTR modulators, whether they or their loved ones benefitted from these therapies or not.

Preliminary results were first presented as an abstract and during a NACFC workshop. Next steps include publishing multiple manuscripts to inform future research.

Well-ME was developed after hearing stories from the community about the impact that modulators have on their lives, whether they have access to them or not.

It was critical to partner with the CF community to build the survey, so results captured meaningful changes to well-being that the community experienced the past few years.

This is a perfect example of how partnership with community can drive success of a research effort, and I look forward to seeing how this work will launch future community partnerships.

Elizabeth Yu, Clinical Training and Resources Director, Clinical Trials

People currently taking a CFTR modulator report improvements in many domains of well-being

<table>
<thead>
<tr>
<th>Domain</th>
<th>Overall Health</th>
<th>Quality of Life</th>
<th>Physical Well-being</th>
<th>Burden of Care</th>
<th>Social Well-being</th>
<th>Mental Well-being</th>
<th>Financial Well-being</th>
</tr>
</thead>
<tbody>
<tr>
<td>% better/worse</td>
<td>4%</td>
<td>5%</td>
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<td>6%</td>
<td>8%</td>
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<td>40%</td>
<td>22%</td>
<td>22%</td>
<td>17%</td>
<td>10%</td>
</tr>
<tr>
<td>% worse</td>
<td>44%</td>
<td>39%</td>
<td>34%</td>
<td>23%</td>
<td>12%</td>
<td>7%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Analyses limited to people currently taking a modulator therapy (n=718)
IMPROVING CF CARE

Guidelines
This year, the Foundation sought input from Community Voice to inform manuscript drafts and clinical care guidelines and provide public comment on topics including nutrition:

1. **Nutrition Survey (Input on draft manuscript: CF Foundation Nutrition Position Paper)**
   This position paper is intended to provide interim guidance and considerations on emerging and changing areas of CF nutritional care.

2. **Liver Guidelines (Guidelines for Screening, Monitoring and Treatment of Hepatobiliary Disease in Cystic Fibrosis)**
   A committee of CF hepatology, and gastroenterology health care providers, an adult with CF, and a parent of an individual with CF researched and developed the consensus recommendation statements for the management of CF-associated hepatobiliary complications, which then sought public comment through Community Voice.

3. **Models of Post-Transplant Care for Individuals with Cystic Fibrosis White Paper**
   This committee of international experts in CF and lung transplant care investigated shared models of post-transplant care and distributed an international survey to clinical and patient/family audiences to determine preferences for various models of post-lung transplant care. Their white paper was then distributed for public comment through Community Voice.

4. **Ear, Nose, and Throat (ENT) Area of Focus Document Feedback**
   Community members provided feedback on a document developed by the CF Foundation ENT Guidelines Committee. This document was used to inform the CF community, both researchers and patients and families, of research topics identified as areas of focus to advance our knowledge and address research gaps related to CF sinus disease.

Further Reading:

**North American Cystic Fibrosis Conference:** Community Voice members are involved in several ways at NACFC, including as members of the program planning committee, speakers, researchers, and major contributors to data presented. This year four members contributed to a particularly powerful session on Culturally Aware CF Care. Learn more about the various places where Community Voice had an impact at the conference.
In 2022, Community Voice launched a diversity awareness effort to recognize and celebrate the rich diversity within the CF community and promote an inclusive and welcoming environment for all members to continue using their voice to shape work across the CF Foundation.

Expanding access to Spanish Language Content: For more than 5 years, 9 adults with CF and parents of children with CF in Community Voice have supported the Spanish-speaking CF community by reviewing Spanish-translated materials to ensure that the content is coherent, culturally appropriate, and lay-friendly. This group has also helped in vetting work from Spanish-translation vendors to inform the selection of a vendor which will dramatically expand and improve content available in Spanish on cff.org.

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SUPPORTING OTHERS WITHIN THE CF COMMUNITY

The CF Adult Advisory Council (AAC) welcomed four new members from Community Voice to represent the multifaceted perspectives and experiences of adults with CF. In 2022, the AAC helped shape virtual content for several Volunteer Leadership Conference (VLC) sessions, one of which they hosted, and evaluated Impact Grants applications for potential programs focused on benefitting the CF community.

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From top left: Leah Aiken, Giovanni Peralta, Jen Eisenmann, Leisha Cuddihy, Teena Mobley, Kristin Dunn, Tré LaRosa, Raeshun Jones, Katie Fielding, Will Corcoran, Kathy Shannon, Tony Madonna, Steve Larson, KC White
**Community Conferences:** FamilyCon Program Planning Committee expanded representation at the conference through Community Voice recruitment. These committee members focused on topics relevant to the many, diverse experiences of the CF community that may have gone unmentioned before. Additionally, these members assisted the Community Conferences team with attracting new and diverse speakers – allowing more attendees to see and hear from others like them.

“An amazing opportunity to provide feedback to those making decisions about care. Also an incredible chance to interact and meet others with CF.” – Mark Levine, Community Voice Member

“I feel like I’m able to give back and be one of the many that can help the future of CF through my past experiences and knowledge that I have learned along the way.” – Seth Gregory, Community Voice Member

“It helps me stay positive, focused, and this may sound inappropriate but excited for CF. I say excited because I look forward to updates on medicines, results, and it takes the fear away.” – Lili Hunt, Community Voice Member

26 members shared their experiences with CF through 28 blog posts on the CF Community Blog on a range of topics:
- Lung Transplantation
- Self-Image
- Parenthood
- Exercise
- Rare Mutations
- Living Longer with CF
- And much more.

**Further Reading:**
- Redefining Myself After Lung Transplant by Larissa Marocco
- Giving You Permission to Accept my Chronic Illness by Luisa Palazola
- Making Lifelong Friendships with Other Moms of Kids with CF by Margarete Cassalina
- How My Exercise Capacity Improved After Going on Oxygen by Brian Armstrong

**CF Peer Connect program:** Fifty-seven members served as peer mentors where they provided one-to-one virtual peer support for people with CF and their family members on topics such as daily life with CF, new diagnosis (pediatric and adult), and parenting.

**Community Voice Participation in Community Conferences**
- 181 Community Voice members attended at least one conference
- 34 Community Voice members served on a workgroup
LOOKING AHEAD

In the year ahead, Community Voice will continue to play a critical role in the partnership between the CF community, CF Foundation, and researchers to improve the lives of all with CF. There are several areas that will be of particular focus throughout 2023 including:

Reducing health disparities: The CF Foundation will continue to partner with the CF community to advance work on critical topics such as addressing health disparities that exist based on race/ethnicity, expanding knowledge and resources around social factors that impact health, and developing resources for community members and clinicians.

Informing the Development of New Therapies: As genetic therapies and other treatments to address the complications of CF advance, researchers will continue to bring the community in to help inform priorities, study design, and education around the evolving research landscape.

Improving Care: Community members will continue to play numerous roles in the work to improve care, from reviewing research grant applications, to informing study priorities and design. Projects coming up include topic such as CF related diabetes, reducing treatment burden, improving management of pulmonary exacerbations, improving screening for mental health, sinus disease and more.

Addressing the Full Person: As the CF experience continues to change, there is increased focus on understanding and addressing challenges like mental health, aging, food and financial security, and overall wellbeing. Many projects on the horizon in 2023 continue to address these areas in partnership with the community.

Ensuring representation of the Full CF community: Community Voice is committed to ensuring that all individuals in the CF community have the opportunity to be heard. This is why we will continue focusing on growing the program, implementing new strategies for equitable recruitment in committees, and launching the Community Voice program in Spanish.
The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high-quality, specialized care.

Encourage others to join Community Voice!

If you know others who want to get more involved and help shape research, care, and programs, please encourage them to join by visiting cff.org/CommunityVoice.