



COMMUNITY VOICE

2021 YEAR IN REVIEW



YOUR VOICE, YOUR IMPACT.



As I reflect on the progress Community Voice has made since it was first established in 2014, I am in awe of how much the program has grown and the impact that the voices of the cystic fibrosis community have made across the CF Foundation.

Your commitment to sharing your insights and expertise ensures that together we are charting the fastest course to improving the lives of all people living with CF and their loved ones. Whether you have spent five minutes completing a survey or hours serving on a committee, your time and effort is valued.

You make it possible for researchers, clinicians, and all those supporting the CF community to stay grounded and driven by the wisdom and experience that only those living with the disease hold.

In 2021, we continued to work alongside all of you to find new ways to advance our work in research, care, and community support programs. We also prioritized growing and diversifying the membership of Community Voice, enhancing the recognition and experience of members, and amplifying the program's utilization and impact. Throughout this report, you will find examples of how we have achieved success in these areas, where your contributions have made a difference, and how we are collectively making an impact to advance CF research, care, and programs.

As we look towards 2022, and the ongoing challenges that face the community, we will continue to build on this progress and address the changing needs of adults with CF and their loved ones. We learned a lot about the disparities that exist within the CF community based on race, ethnicity, mutation types, and other factors. We will work to empower and create more opportunities to amplify the voices of individuals who have not had adequate support or representation in our work in the past.

We have already identified several new, exciting projects for 2022, including studying the holistic effects of those who are taking Trikafta®, informing research needs over the next five years, addressing disparities in CF care, and much more. I hope this report leaves you inspired to keep sharing your voice this year.

With gratitude,

Christina Román
Director, Community Insights and Partnering

THE COLLECTIVE POWER OF COMMUNITY VOICE

84%

of Community Voice members engaged
in some way in 2021, with:

300 members participating in a project for their first time

700+ members completing at least one survey

↳ 2,500+ total survey responses submitted

156 members serving across 36 national committees/workgroups

↳ 17 recruitments that added 81 members in 2021 alone

Community Voice members participated in more than 85 opportunities,
including:



25 projects focused on enhancing the design of
CF research studies or care interventions



17 projects on improving CF education and resources
for the community



4 projects about the gastrointestinal system on topics
such as nutrition and simplified treatments



6 projects regarding COVID-19

COMING TOGETHER AS A COMMUNITY

As we continue to adapt to new ways of living due to the pandemic, Community Voice members have stayed focused on connecting with and supporting one another to navigate the complexities of life with CF by sharing countless stories, personal experiences, and valuable insights.



KNOWING THAT OUR WORK AT THE CF FOUNDATION IS BETTER BECAUSE WE ARE HEARING FROM A DIVERSE COMMUNITY WITH DIFFERENT BACKGROUNDS AND PERSPECTIVES, PROFESSIONAL EXPERTISE, AND LIVED EXPERIENCES BRINGS ME SO MUCH JOY.

 **Sue Sullivan**, Vice President and Head of Community Partnerships

BUILDING AN INCLUSIVE COMMUNITY

CF affects people of many different backgrounds, and there are unique needs and perspectives of every person in the community. The CF Foundation embraces hearing from all voices and is committed to engaging with CF community members who have been historically underrepresented, increasing efforts around listening and transparency, and addressing health disparities in CF research and care. By fulfilling this commitment, the CF community can foster a stronger sense of belonging and help create a space where everyone is welcomed, respected, supported, and valued.

Throughout 2021, we prioritized hearing from underrepresented voices in the CF community and understanding engagement barriers with CF Foundation programs like Community Voice. Two engagement groups were established to support our targeted listening efforts, including one for those who are not currently benefiting from highly effective CFTR modulators and another for people of color with CF and their family members.

FOCUSING ON HEALTH EQUITY

In July, focus groups were conducted with people of color in the CF community to hear about their engagement experiences with the CF Foundation and care centers. These conversations revealed the need to evaluate the organization's processes for committees, workgroups, and workshop recruitments, identify more opportunities to improve our engagement efforts for racial and ethnic minority groups, and educate CF researchers and clinicians about the importance and benefit of ensuring all voices of the community are present in their work.

BEING AN AFRICAN AMERICAN WOMAN WITH CF, IT HAS BEEN WONDERFUL TO BE A PART AND BE ABLE TO REPRESENT FOR OTHERS THAT LOOK LIKE MYSELF. DOING THIS WORK HAS ALLOWED PEOPLE OF COLOR TO BE INCLUDED IN DECISION MAKING AS WELL AS THE BEST CARE.



I THINK IT IS EXTREMELY IMPORTANT FOR INDIVIDUALS IN THE COMMUNITY TO GET INVOLVED SO THAT OUR OPINION IS RECOGNIZED WHEN DECISIONS ARE MADE.

 **Raeshawn Jones**, Community Voice Member and Adult Advisory Council Member

COMING TOGETHER AS A COMMUNITY • continued

Dedicated outreach efforts throughout the year led to doubling diverse membership in Community Voice, increasing opportunities for those who are not currently benefiting from modulators, and improving recruitment practices for more diverse representation on committees, workgroups, and workshops.

For more than four years, Community Voice members have played a critical role to support the Spanish-speaking CF community through serving on the Spanish Language Community Review Committee. This year, members provided insight related to the content and resources available on cff.org for the Spanish-speaking community and reviewed a translated resource on supporting mental health in adolescents during the pandemic.

EMPHASIZING THE NEEDS OF THE CF COMMUNITY

To stay informed of the needs of the multifaceted community, especially adults with CF, the Foundation works closely with the **CF Adult Advisory Council (AAC)**, a rotating group of adults living with CF who are members of Community Voice. The AAC serves as a consultative body that advises organization-wide leaders on a variety of areas. In 2021, their work included creating outreach strategies for community programs, providing insights on the redesign of cff.org, and creating virtual engagement tactics for organization events. This group also shared their perspectives and insights on emerging priorities like genetic based therapies and wellness.



From top left: Leah Aiken, Gabriella Balasa, Ed Canda, Leisha Cuddihy, Teena Mobley, Kristin Dunn, Tré LaRosa, Raeshaun Jones, Katie Fielding, Somer Love, Kathy Shannon, Tony Madonna, Lydia Sand, KC White

Additionally, the council supports the Foundation's **Impact Grants** program by reviewing applications for potential programs focused on benefitting the CF community. A broader group of Community Voice members also supported the Impact Grants program by participating in a survey to identify the community's priorities and areas of need for future grant submissions.

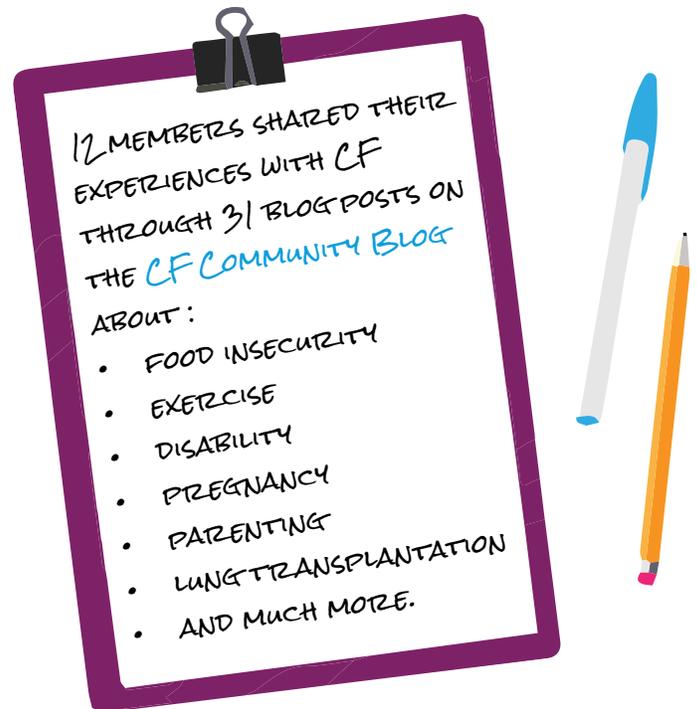
SERVING ON THE AAC GIVES ADULTS WITH CF THE CHANCE TO MEET WITH CF FOUNDATION STAFF AND IT IS EVIDENT THROUGH OUR COLLABORATIONS THAT OUR EXPERTISE IS HIGHLY VALUED.

FOR ME, THE BEST PART OF SERVING ON THE COUNCIL IS CONNECTING WITH OTHER ADULTS WITH CF FROM ALL OVER THE COUNTRY TO SHARE OUR MANY DIFFERENT UNIQUE AND IMPORTANT PERSPECTIVES.

The needs of the CF community were also highlighted through policy and advocacy work. Interviews with Community Voice members were used as case studies to educate insurance companies about how to reduce negative health impacts so that people with CF do not experience gaps in CF care while going through the insurance approval process. Members also shared their stories to help raise awareness about the need for new antibiotics to treat frequent and chronic infections, which have become increasingly difficult to address due to existing ineffective antibiotics.

SUPPORTING EACH OTHER THROUGH SHARED EXPERIENCES

Members shared their stories of life with CF to connect with and offer support to others dealing with similar experiences. Twenty three members helped shape virtual **community conferences** where community members of many different backgrounds came together to find support, have candid conversations, and make meaningful connections. Additionally, 101 members also served as mentors to provide one-to-one virtual peer support for people with CF and their family members through **CF Peer Connect** and helped expand the program to better support those who are post-lung transplant.



EMPOWERING OTHERS WITHIN THE CF COMMUNITY

Empowering clinicians, patients, and caregivers of people with CF through awareness and education is an essential component to promote health equity and improve disease management. Community Voice members played a critical role in developing resources for the CF community, with a large focus this year on informing the redesign of **cff.org** to better support people with CF. Community members at different stages in their CF journey provided input to improve the user experience, especially for those who are newly diagnosed, so that the community can better find the information and support they are looking for when visiting the website.



BEING A PART OF COMMUNITY VOICE HAS BEEN INVALUABLE AND HELPS ME DO EVERYTHING I CAN TO MAKE SURE THAT THE KIDS NOW LIVING WITH OR BEING BORN WITH CF NEVER GO THROUGH THE CHALLENGES THAT MY FRIENDS AND I EXPERIENCED GROWING UP.

MAINTAINING THE MOMENTUM

PROGRESS IN RESEARCH & CARE

ADAPTING CF CARE IN THE ERA OF COVID-19 & TRIKAFTA

Over the past two years, many CF researchers and clinicians have sought to understand how the pandemic and expansion of Trikafta® have affected daily CF care. The risk of exposure to COVID-19 has led to increased use of telehealth and home-based research, so it has become increasingly important to hear from the community regarding the use of telehealth to increase access to care and reduce barriers to clinical trial participation.

Researchers from the real-world research (RWR) HERO-2 study, which collects daily observations about treatment and symptoms through a phone-based app, recruited CF community members to inform its study design and recruitment materials. Findings from this study will provide insight into the changes that people with CF are making to their care regimen after starting Trikafta®.



THE GOAL OF REAL-WORLD RESEARCH IS TO TRULY UNDERSTAND THE REAL-LIFE EXPERIENCES OF PEOPLE WITH CF.

WE ARE GRATEFUL TO COMMUNITY VOICE MEMBERS FOR HELPING TO CO-DESIGN AND IMPLEMENT THE FOUNDATION'S FIRST RWR STUDY, HERO-2, AND MAKE IT A MORE INCLUSIVE OPPORTUNITY THAT WILL INFORM THE CONTINUED EVOLUTION OF CF CARE.

 **Linh Do**, Clinical Research Program Manager about impact of HERO-2 Study

In addition to learning more about changes to overall daily care regimens, Community Voice members participated in a survey to help evaluate the views of patients and providers regarding exercise as part of a treatment plan for airway clearance, especially for those on Trikafta®. Members also weighed in on two projects aimed at improving access and assessing feasibility of utilizing home sputum collection and home spirometry for clinical research. These projects are informing clinical trial studies that are accounting for changes in sputum production among those taking Trikafta® and study procedures that can be done outside of the clinic.

COLLECTING SPUTUM IS VALUABLE IN CLINICAL CARE AND RESEARCH BUT HAS BECOME DIFFICULT AS PEOPLE TAKING CFTR MODULATORS FEEL BETTER AND PRODUCE LESS SPUTUM.



COMMUNITY VOICE MEMBERS HELPED US UNDERSTAND THE PATIENTS' PERSPECTIVE AND THAT THOSE WHO CAN'T PROVIDE SAMPLES WHEN ASKED IN CLINIC ARE ABLE AND WILLING TO COLLECT SPUTUM AT HOME. THIS HAS PROVED UNBELIEVABLY VALUABLE AS WE SUPPORT EFFORTS THAT DEPEND ON THESE COLLECTIONS.

 **David Nichols**, Medical Director of the TDN Coordinating Center at Seattle Children's Hospital
 **Chris Goss**, Co-Executive Director of the TDN Coordinating Center at Seattle Children's Hospital

MAINTAINING THE MOMENTUM • continued

PROGRESS IN RESEARCH & CARE

In partnership with Community Voice members, we continue to pivot to the evolving needs of people living with CF during these unprecedented times. Members continue to advise the Foundation on its pandemic response by serving on the COVID-19 Medical Advisory Group. This group discusses the critical and rising trends of the coronavirus at the clinic and health system levels, provides recommendations through the Foundation's [COVID-19 Community Questions and Answers](#) webpage, and advises on potential interventions that support the community, such as providing support to care centers to purchase hand-held spirometers for their patients.

ENHANCING CF CARE BY PARTNERING WITH CLINICIANS

Community Voice members have been critical partners in ensuring that people with CF receive comprehensive, high quality, and specialized care. To support this effort, members informed the redesign of the [Experience of Care Survey](#) which focuses on the patient and caregiver experience during in-person and virtual clinic visits. Not only are Community Voice members serving on the Steering Committee to support this research, but they also reviewed both the English and Spanish versions of the survey to ensure clarity, inclusivity, and cultural competence before it was broadly disseminated. An ongoing analysis of this survey is helping CF care providers, clinicians, and researchers better understand patient concerns about infection prevention and control, general communication challenges, and the overall quality of the care experience.



THE EXPERIENCE OF CARE SURVEY IS A GREAT OPPORTUNITY TO SHARE YOUR THOUGHTS REGARDING YOUR CARE EXPERIENCE ANONYMOUSLY WITH YOUR TEAM.

WE LOVE THE FEEDBACK WE'VE BEEN GETTING FROM THE COMMUNITY BECAUSE WE'RE LEARNING ABOUT WHAT HAS BEEN GOING WELL AND WHAT ARE THE MOST PRESSING NEEDS RELATED TO IMPROVING CARE FOR ALL PEOPLE WITH CF.

 **Domonique Gamory**, Quality Improvement & Innovation Analyst

Through the work of the Education Committee and alongside CF care team members across various disciplines, Community Voice members have supported the development and implementation of educational materials available for CF community members in clinic on topics such as mental health, nutrition/gastrointestinal issues, transplantation, and many other topics.

Members also continue to be key contributors throughout the entire development process for [CF Clinical Care Guidelines](#) by serving on a committee of experts, prioritizing areas to address gaps in care, and providing feedback on the guidelines themselves. In 2021, members began serving on the Pain Management Guidelines Committee to focus on pain assessment, management, and communication in clinical care settings and participated in a public comment opportunity for care guidelines around ear, nose, and throat concerns ahead of its publication.

MAINTAINING THE MOMENTUM • continued

PROGRESS IN RESEARCH & CARE

As part of a new scope of work moving forward, Community Voice members are supporting the educational content developed from recommendations in published Clinical Care Guidelines. This year, more than ten Community Voice members joined the newly launched Advanced CF Lung Disease Community Working Group to help build lay-friendly resources for the CF community.

TOPIC SPOTLIGHT: NUTRITION & GASTROINTESTINAL ISSUES

In the era of highly effective CFTR modulators, the impact of these therapies on the gastrointestinal (GI) system has become a large focus for researchers. In 2021, Community Voice members informed a study that examined the changes and simplifications of daily care and treatments for people with CF who experience GI complications.

Researchers from the University of Texas also conducted a survey to assess the need for further research into the simplification of GI medications for people with CF, particularly acid suppressive medications and pancreatic enzyme replacement therapies (PERT). Through the insights of Community Voice, this study determined that the community is interested in how the use of these medications can be safely reduced for those currently benefitting from modulator therapy.

HEARING FROM COMMUNITY VOICE MEMBERS GRANTED US THE OPPORTUNITY TO BETTER DESIGN A STUDY THAT WILL ALLOW US TO CREATE EVIDENCE AROUND THE ABILITY TO SAFELY STOP ACID SUPPRESSIVE MEDICATIONS AND MAKE A TRUE IMPACT ON THE COMMUNITY WE AIM TO SERVE.



COLLABORATING WITH PEOPLE WITH CF AND THEIR LOVED ONES THROUGH COMMUNITY VOICE IS A TRUE TESTAMENT TO THE MEANING OF CO-PRODUCTION.

 **Meghana Sathe**, Pediatric Gastroenterologist and Co-Director of the CF Clinic and Therapeutics Development Center, Pediatric Program at the University of Texas Southwestern

With more than 85% of people with CF experiencing exocrine pancreatic insufficiency, researchers from Synspira Therapeutics also conducted a study to better understand PERT usage in the CF community. This survey examined what is important to the CF community regarding how PERTs work, the willingness to participate in clinical trials for new PERTs, the perspectives on potential new PERTs, and how nutritional statuses are measured in CF patients that utilize PERTs.

MAINTAINING THE MOMENTUM • continued

PROGRESS IN RESEARCH & CARE

FOCUSING ON ADVANCED CF LUNG DISEASE & TRANSPLANTATION

Being well-informed and feeling prepared is crucial for making decisions surrounding lung transplantation. Through a two-pronged survey completed by people with CF and caregivers in Community Voice -- both with and without lung transplant experience -- researchers at the University of Washington gained valuable insight into the community's perspectives and experiences surrounding the decision-making process of receiving a lung transplant. Members also served on a work group to design and pilot a resource to help people with CF prepare for discussions with their doctors about deciding to have a lung transplant.

Community Voice members also began serving on the CF Lung Transplant Consortium Steering Committee in 2021. As members of this committee, people with transplant experience help the Foundation establish a group of lung transplant centers committed to improving outcomes of lung transplant and promote relationships between CF and lung transplant care teams. Additionally, Community Voice members started serving as grant reviewers for the Chronic Lung Allograft Dysfunction (CLAD) Biomarkers Review Committee to provide feedback on proposal's feasibility and relevance to people with CF who have received a lung transplant.

BOTH COMMITTEES
FOCUS LARGELY ON
CHRONIC LUNG
ALLOGRAFT DYSFUNCTION,
A COMMON
POST-TRANSPLANT
COMPLICATION AND
RISING PRIORITY FOR
THE FOUNDATION'S
LUNG TRANSPLANT
BIOREPOSITORY AND
PATIENT REGISTRY.



THE ESSENTIAL PARTNERSHIP WITH COMMUNITY VOICE MEMBERS HELPED US STAY LASER-FOCUSED ON ADDRESSING THE NEEDS OF PEOPLE LIVING WITH ADVANCED CF LUNG DISEASE AND THOSE WHO HAVE RECEIVED LUNG TRANSPLANTS.

YOUR TIME, PROFESSIONAL EXPERTISE, AND LIFE EXPERIENCES HAVE HELPED US UNDERSTAND TOPICS SUCH AS THERAPIES AND PROCEDURAL BURDEN (BOTH IN CARE AND RESEARCH), RELEVANCE OF RESEARCH TOPICS, AND HOW TO DESIGN STUDIES THAT ALIGN WITH THE EXPERIENCE OF PEOPLE WITH CF.

MAINTAINING THE MOMENTUM • continued

PROGRESS IN RESEARCH & CARE

UNDERSTANDING MENTAL HEALTH & WELL-BEING

The need to focus on one's mental health has become increasingly prominent over the past two years, and Community Voice members played a vital role in prioritizing and influencing the direction of mental health research for people with CF and their loved ones. In 2021, members partnered with researchers and CF clinicians to better integrate mental health tools and resources into CF care by focusing on topics such as:

- Mental health screening and follow-up care
- Mental health challenges and identity development for teens and young adults with CF
- The triggers and manifestations of medical traumatic stress
- Future interventions to address a variety of these topics
- Mental health during the COVID-19 pandemic

INFORMING RESEARCH ON CF CARE

Throughout 2021, Community Voice members shaped research studies focused on improving CF care and treatments. This included studies where members:

- Provided feedback on recommendations aimed to improve access to CF genetic counseling with a focus on parents of infants who have had a positive CF newborn screening result
- Shared insights on pulmonary exacerbation treatment and management for the STOP-3 study
- Provided input on home-based stool collection for cancer screening to inform an upcoming clinical trial
- Shared experiences with urinary incontinence to help advance research
- Participated in study design days for behavioral interventions (like mobile health) to help sustain the daily care and self-management of CF

Community Voice members have also been an integral piece of nearly every aspect of the **Infection Research Initiative** since its inception in 2018. Most recently, members participated in a survey to provide meaningful insights that are informing how the Foundation communicates about infection research and the priorities of this initiative, whose robust research portfolio has exceeded more than \$100M in funding.



KEEPING THE COMMUNITY'S LIVED EXPERIENCES
FRONT AND CENTER HAS BEEN ESSENTIAL IN MOVING THE NEEDLE
ON INFECTION RESEARCH.

HEARING DIRECTLY FROM THOSE WHOM THIS INITIATIVE
AFFECTS THE MOST HAS BEEN HUMBLING AND CRUCIAL
IN REAFFIRMING OUR PRIORITIES AND GOALS
FOR 2022 AND BEYOND.

PROJECT SPOTLIGHT: Genetic Based Therapies

As we progress on a path to a cure, we have seen major scientific advances towards the development of genetic therapies for CF such as RNA therapy, gene editing, and gene therapy. As clinical trials are developed for these potential therapies, it is imperative we continue to hear from all in the CF community, including those who are currently not benefitting from modulators. Community Voice members have played a key role in informing the Foundation's next steps in genetic therapy through major surveys, working groups, and focus groups.

CF CLINICAL RESEARCH IS ENTERING A NEW PHASE IN WHICH NOVEL GENETIC-BASED TREATMENTS WILL BE ENTERING CLINICAL TRIALS. IT HAS NEVER BEEN MORE IMPORTANT THAN NOW TO HEAR THE VOICE OF THE CF COMMUNITY IN THESE EXCITING NEXT STEPS.



 **JP Clancy**, Vice President of Clinical Research



Over the past two years, the Foundation has evaluated the community's understanding, perspectives, and willingness to participate in genetic therapy studies through a survey that collected more than 500 responses from adults with CF and their caregivers. Results from this study highlighted the need to increase efforts in educating and informing the CF community about the science behind genetic therapies, as well as the risks and benefits of participating in clinical trials in this space.

The Genetic Based Therapies Working Group was also created in 2021 to holistically address the needs of researchers and the CF community surrounding genetic therapies. Members serve as key stakeholders on two subgroups dedicated to education efforts. They are tasked with informing educational resources for care teams and the CF community, while also advising industry sponsors on trial design and feasibility.

COMMUNITY INSIGHT IS CRITICAL TO DEVELOPING AN EFFECTIVE COMMUNICATIONS CAMPAIGN AROUND GENETIC THERAPIES FOR CF.



COMMUNITY VOICE MEMBERS WILL BE INSTRUMENTAL IN ENSURING WHAT WE ARE COMMUNICATING IS ACCESSIBLE AND RESONATES WITH OUR INTENDED AUDIENCE, THE COMMUNITY.

 **Genevieve Maul**, Director of Communications

As part of the next phase, the working group conducted focus groups with more than twenty members to identify the gaps in understanding regarding clinical trials for CF genetic therapies and any potential barriers to participation. Thanks to the partnership of Community Voice members and this working group, researchers and the CF Foundation are identifying what is most important to the CF community and how to chart the course for expanding treatment options for CF – particularly for those who are not currently eligible for modulators. As we look towards the future, your support and partnership will continue to be vital as we advance the next generation of transformative CF therapies.

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.



**CYSTIC FIBROSIS
FOUNDATION®**

4550 Montgomery Avenue
Suite 1100N
Bethesda, MD 20814

1.800.FIGHT.CF
cff.org/CommunityVoice