

2020

YEAR IN
REVIEW



THANK YOU, COMMUNITY VOICE MEMBERS



Every time you choose to participate in a project with Community Voice, you make a difference. Community Voice members embraced many new challenges in 2020, including the COVID-19 pandemic, social unrest, and shifts to a virtual world. As a member, you continue to demonstrate resilience that helps make the story of CF so powerful and successful.

Together with members of Community Voice, the CF Foundation has been able to better address what matters most to you. Year after year, you devote your time, energy, and perspective by weighing in on a multitude of topics. 2020 was no different. You helped clinicians, researchers, and CF Foundation staff better understand what resources were needed to navigate the challenges of COVID-19 while staying focused on your top research priorities. In this report, you will find more details about the projects you enhanced in cure, care, and community efforts last year.

No one knows what living with CF is like better than you. We are listening and your voice is heard. For every survey you completed, every focus group you attended, every committee you contributed to, every opinion you shared - thank you. Our work is truly better for it!

Moving into 2021, the CF Foundation is committed to growing and diversifying Community Voice membership. We ask for your help to ensure we hear from every voice by encouraging three CF community members you know to join and improve the future for the entire community together.

With gratitude,

Sue Sullivan, RN, BSN
Senior Director, Head of Community Partnerships

THE COLLECTIVE POWER OF COMMUNITY VOICE

89%

of Community Voice members engaged
in some way in 2020, with:

185

members participating
in a project for the
first time

80

members participating
in a focus group

122

members currently
serving on national
committees

Community Voice members participated in more than **85** projects, including:



16

projects for CF Foundation virtual events on topics such as emotional wellness and sexual and reproductive health research



8

projects regarding COVID-19



8

projects about CF complications such as CF-related diabetes and CF-related liver disease



6

projects focused on enhancing the design of CF research studies

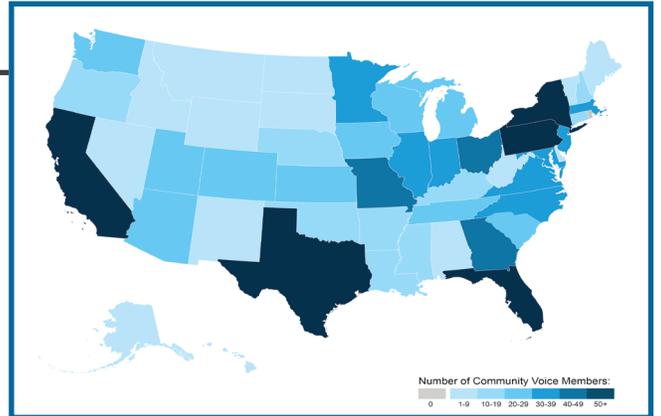


17

committee recruitments, which led to **62** Community Voice members being chosen for national committees

ABOUT COMMUNITY VOICE MEMBERS

1,301
TOTAL
MEMBERS



Learn more about projects that members participated in throughout 2020 in our **Monthly Results Updates!**

Think you missed out on some great opportunities? Receive tailored opportunities that are relevant to you by **emailing us** to update your profile.

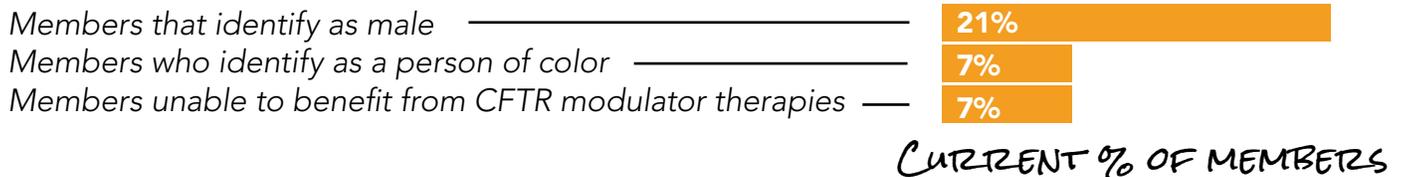
Connection to Cystic Fibrosis*

Person with CF:	45%
Parent of a person with CF:	43%
Spouse of a person with CF:	4%
Other: (grandparents, siblings, children, aunts, uncles, in-laws, friends, etc.)	16%

*Members may have multiple connections to CF.

Every voice matters.

Each person's experience is unique, so it's critical to hear from as many people as possible. Groups with underrepresentation in Community Voice that we are working to better engage include:



Encourage others to join Community Voice!

If you know others who are unable to benefit from CFTR modulator therapies, identify as a person of color within the CF community, is a parent of a young child with CF, or just want to get more involved and help shape research, care, and programs, please encourage them to join Community Voice by visiting cff.org/CommunityVoice.

The CF community's involvement in research increased rapidly in areas such as mental health, sexual and reproductive health, nonsense/rare mutations, and genetic therapies, making it clear that there is a large demand from CF researchers for community input to help inform their projects.

PRIORITIZING & INFLUENCING THE DIRECTION OF RESEARCH

Community Voice members participated in a survey to help researchers from the Foundation and companies developing therapies for nonsense and rare mutations better understand the community's perspective on genetic-based therapies consisting of mRNA therapy, gene-editing, gene therapy, and the willingness to participate in clinical trials. Insights from this project will serve as a starting point as research in this area continues to develop.

Additionally, the urgency for advancing mental health research was especially prominent in 2020 and continues to be a top priority area for the CF community. Care providers and more than 100 Community Voice members participated in a national survey to prioritize and provide insight on topics such as anxiety, depression, mood disorders, treatment burden, the effects of mental health on physical health, and the risk factors and prevalence of mental health conditions in people with CF. This project will help guide researchers to ensure that the Foundation's funding decisions are steered by the needs of the CF community.

IT IS VITAL TO COMMUNICATE WHAT MENTAL HEALTH TOPICS ARE A PRIORITY TO PEOPLE WITH CF TO SHAPE THE APPLICATIONS WE RECEIVE AND WHAT RESEARCH WE FUND.



CF RESEARCHERS WANT TO PURSUE WORK THAT IS MEANINGFUL AND IMPACTFUL TO PEOPLE WITH CF, AND COMMUNITY VOICE MEMBERS HELPED REINFORCE THIS NEED TO THE RESEARCHERS.

 **Dara Riva**, Director of Clinical Research

More than 50 members of Community Voice also served on research-related committees and workgroups for data use and safety, study protocol reviews, studying medical traumatic stress, infection research, and more. The Clinical Research Committee (CRC) continued to make progress toward increasing community representation by expanding to 20 Community Voice members who reviewed and provided feedback on clinical research grant proposals. A new workgroup was also created this year, which focused on addressing gaps in knowledge around women's health research.



SERVING ON THE CRC HAS BEEN A GREAT WAY TO USE MY SCIENTIFIC AND PERSONAL EXPERIENCES AND HELP RESEARCHERS LEARN MORE ABOUT THE BEST WAYS TO TREAT CF.



IT'S ALSO EXCITING TO BE BEHIND-THE-SCENES OF NEW RESEARCH AND GRATIFYING TO HEAR HOW IMPACTFUL MY PERSPECTIVE HAS BEEN FOR THE GRANT REVIEWS AND SCIENTISTS DOING THE WORK.

 **James Lawlor**, Community Voice Member

SHAPING RESEARCH

More people with CF are living longer, healthier lives and re-evaluating their sexual and reproductive health choices. Over 65 women in Community Voice played a vital role in shaping research in this area through projects such as the MAYFLOWERS study. Members informed the study's survey design and took the survey itself to share their perspective on using modulators during pregnancy, childbirth, and other reproductive health outcomes. Men in Community Voice participated in a similar project that focused on their needs and preferences related to sexual health, fertility, and parenthood. Findings from both projects have been critical assets to shape the direction and groundwork for future research and educational resources.

AS MORE WOMEN WITH CF MAKE THE CHOICE TO BECOME PREGNANT, IT HAS BECOME MORE IMPORTANT THAN EVER TO UNDERSTAND HOW HAVING A BABY AND BREASTFEEDING IMPACT A WOMAN'S HEALTH.



THROUGH COMMUNITY VOICE, WE LEARNED WHICH QUESTIONS ABOUT PREGNANCY AND LACTATION MATTERED MOST TO WOMEN WITH CF AND WERE CRITICAL TO INCLUDE IN THE DESIGN OF THE MAYFLOWERS STUDY.

 **Jennifer Taylor-Cousar, MD, MSCS**, Co-PI of MAYFLOWERS Study

DISSEMINATING RESEARCH INFORMATION

Sharing back the results and information about studies is another critical component to enhance collaboration and transparency in research. Members supported these efforts by providing feedback on a resource that highlighted Foundation-supported academic research projects in areas that have been prioritized by the CF community. Additionally, members moderated research webinars that provided updates on sexual and reproductive health, infection research, and CF-related diabetes.

PROJECT SPOTLIGHT: CF-Related Diabetes

CF-related diabetes (CFRD) affects over 35% of adults with CF and is consistently ranked as a high research priority by the CF community. To help advance research on this topic, Community Voice members participated in an extensive, multi-phased project throughout the year.

SHARING PERSPECTIVES & EXPERIENCES

To understand the perspectives and needs of the CF community related to screening, diagnosis, treatment, and management of CFRD, endocrinologists partnered with the Foundation to conduct a series of focus groups. Twenty-five members shared their personal experiences with CFRD, their understanding of treatment, and their top endocrine research and educational support priorities.

These insights informed a national survey that explored the community's preferences on how care providers can improve their educational practices and how diabetes technologies (such as continuous glucose monitors and insulin pumps) are used. Researchers learned that although education is the cornerstone of CFRD management, the frequency of conversations between care providers and patients do not meet the community's expectations. Additionally, the findings revealed that the use of diabetes technologies is increasing among people with CF, which has not been well studied in the community.



LEARNING ABOUT THE PRIORITY OF CFRD RESEARCH AND THE PARTNERSHIPS BETWEEN THE CF FOUNDATION, DOCTORS, AND RESEARCHERS TO HELP TRAIN ENDOCRINOLOGISTS AND FIND BETTER TREATMENT AND MANAGEMENT FOR CFRD WAS A BRIGHT SPOT IN 2020 FOR ME.

 **Meagan Helmick**, Community Voice Member

GETTING THE WORD OUT

The important insights from this project were shared in a research overview [webinar](#) where CF clinicians, researchers, and community members discussed current and upcoming studies about CFRD diagnosis and treatment. NACFC also featured a [session](#) related to CFRD about bionic or artificial pancreas devices that excited members of the CF community.

FUTURE WORK

Researchers will host a workshop to continue identifying research priorities and inform the development of a CFRD-specific Request for Application sponsored by the NIH to shape future research in the field. Additional work is underway to build educational materials about CFRD technologies, develop studies that measure health outcomes, and advocate for better insurance coverage to help mitigate treatment costs related to CFRD. CFRD will also be highlighted throughout [ResearchCon 2021](#).

Community Voice members are partners in ensuring that people with CF experience high quality, comprehensive, and specialized CF care.

INFORMING CF CLINICAL CARE GUIDELINES

Members continue to influence CF Clinical Care Guidelines by informing their scope, serving on various committees, and participating in public comment and summary reviews before final publication. This year, members shared their insights to contribute to guidelines on CF liver disease, pain and symptom management, and post-lung transplant care. There were **eight publications** that highlighted the CF community's involvement and four active committees focusing on the development of clinical care guidelines.

SOCIAL DETERMINANTS OF HEALTH & HEALTHCARE POLICY

Members provided insight into the challenges people with CF face when accessing quality CF care. In August, two members shared personal testimony to the Institute for Clinical and Economic Review's (ICER) public meeting on CFTR modulators. Their stories helped ICER understand daily life with CF and how transformative modulator therapies can be for those who are eligible, particularly around quality of life and mental health. Additionally, both the Food Security Committee and Access Steering Committee added new members through Community Voice. Five caregivers and four adults with CF are contributing their unique perspectives to these multidisciplinary groups to help improve food security and ensure all people with CF can access high quality health care.

CF CARE IS CHANGING RAPIDLY AND OUR MISSION IS TO MAKE SURE EVERYONE CAN ACCESS THE BEST POSSIBLE CARE AVAILABLE.

COMMUNITY VOICE MEMBERS BROADENED OUR PERSPECTIVE BY INFUSING OUR WORK WITH REAL-LIFE EXPERIENCES TO HELP KEEP PEOPLE WITH CF AT THE CENTER OF ALL WE DO.



 **Anne Willis**, Senior Director, Health System Innovation & Navigation

ADDITIONAL CF-CARE RELATED PROJECTS

Members participated in additional CF-care related projects in 2020 by:

- Contributing ideas for how the CF Foundation and CF care teams should measure and monitor wellbeing and health outcomes for people with CF
- Identifying methods to improve the accessibility and use of clinical data
- Sharing perspectives and experiences regarding the lung transplant process, including information needs and communication preferences
- Ranking applications that can help support the self-management of daily CF care

COMMUNITY

In 2020, it was more crucial than ever for people with CF and their loved ones to come together and support one another. Community Voice members shared countless stories, personal experiences, and valuable insights to help support the community through new and extraordinary challenges.

SUPPORTING ONE ANOTHER THROUGH SHARED EXPERIENCES

Members continued sharing their stories of life with CF to connect with and offer support to others who may be dealing with similar experiences. Twenty-nine members wrote 42 posts for the CF Community Blog on topics such as life on Trikafta, life during COVID-19, sexual and reproductive health, and much more. Seventeen members also facilitated breakout sessions at virtual [community conferences](#) and 85 members served as mentors through [CF Peer Connect](#) to provide one-to-one virtual peer support.

A group of adults with CF from all over the country, including 14 who are a part of Community Voice, gathered virtually to create the ROSE UP event. Inspired by the strength and resilience that the CF community displayed during the pandemic, this new fundraising initiative provided an opportunity for people to come together and connect online.

ROSE UP IS ANOTHER EXAMPLE OF WHAT THE CF COMMUNITY CAN ACCOMPLISH WHEN WE JOIN TOGETHER.

PEOPLE ROSE UP FOR A CURE IN MANY CREATIVE WAYS - BIKING, BAKING, PERFORMING POETRY, CANNONBALLING INTO A POOL OF ROSES, AND GENEROUSLY DONATING CRITICAL FUNDS SO THAT WE CAN CONTINUE CF RESEARCH THAT WILL LEAD TO A CURE FOR ALL PEOPLE WITH CF.



IT WAS OUR FAVORITE DAY OF 2020 AND WE CAN'T WAIT FOR NEXT YEAR!

🌻 **KC White, Marissa Benchea, and Somer Love**, Community Voice Members

EMPOWERING THE CF COMMUNITY

To help empower people with CF and their caregivers to direct their health, members played a critical role in resource development. This included sharing stories to advocate for an expansion of Paid Family and Medical Leave policies during the pandemic and helping to update resources available through *Compass*. Members also serving on the Spanish Language Community Review Committee diligently reviewed materials about COVID-19, racial justice work, and CF care to help ensure more resources on [cff.org](#) are available for our Spanish-speaking members of the CF community.

CRUCIAL TOPICS IN 2020

CORONAVIRUS (COVID-19)

The pandemic caused significant concern for the CF community by raising uncertainties such as the potential risks of contracting the virus, access to CF care, and new challenges around school and work. Thanks to the feedback of Community Voice members, several resources and opportunities were developed to support the CF community in navigating the impacts of COVID-19 in their daily life.

IN 2020, WE REALIZED MORE THAN EVER HOW ESSENTIAL IT IS TO PARTNER WITH THE CF COMMUNITY. YOUR VOICE WAS HEARD THROUGHOUT MANY TIMELY TOPICS SUCH AS MENTAL HEALTH, CF-RELATED DIABETES, THE FUTURE OF GENETIC BASED THERAPIES, AND MOST IMPORTANTLY THE IMPACT OF THE COVID-19 PANDEMIC ON PEOPLE WITH CF AND THEIR FAMILIES.



HIGHLIGHTING THE VOICE OF CF COMMUNITY MEMBERS IN SUCH UNPRECEDENTED TIMES HAS BEEN CRITICAL AS WE CONTINUE TO MOVE THE WORK OF THE CF FOUNDATION FORWARD AND SHAPE OUR UPCOMING PRIORITIES IN RESEARCH AND CARE.

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

COMMUNITY RESOURCES

During this unprecedented time, questions were raised about how COVID-19 would affect people with CF and their families. Community Voice members gave input on an evolving [resource](#) in both English and [Spanish](#) to address timely concerns such as prevention and safety, CF care, vaccines, and more.

Additionally, nearly 30 members informed the development of a [risk assessment tool](#) specifically created for the CF community to help guide discussions with care teams on how to evaluate the risk of activities based on personal risk tolerance and circumstances related to COVID-19.

		RISK BASED ON LENGTH OF CONTACT		
		LOW: Minimal contact (e.g., passing someone on the street)	MED: Intermediate contact (e.g., briefly speaking with someone face to face)	HIGH: Continuous contact (e.g., remaining in proximity (10ft) to others for several minutes or longer)
RISK BASED ON TYPE OF CONTACT	HIGH: Contact with large groups or strangers			
	MED: Contact with small groups of known individuals			
	LOW: Contact with immediate household members			

See the latest on the COVID-19 pandemic and the CF community: <https://on.cff.org/COVID-19>

COMMUNITY CONNECTION

People living with CF were well practiced at physical distancing long before the pandemic and understand the important role that social connection plays in emotional wellness. This expertise supported several virtual events that connected thousands of people in the CF community.

Community Voice members played a vital role in these events by:

- Moderating two emotional wellness webinars that focused on maintaining well-being and how to cope with stress, uncertainty, and anxiety
- Moderating the community Q&A pop-up event that addressed questions regarding the latest medical information, insurance, work, and financial challenges
- Hosting a CF community happiness hour where people shared moments of joy and tips for self-care, working from home, and parenting
- Developing and facilitating a webinar where clinical experts discussed the risks, benefits, key factors to consider, and other concerns about schools reopening/in-person learning

COVID-19 VACCINE

People with CF, their families, and CF care providers participated in a survey to share their thoughts and concerns around a potential vaccine. Once the U.S. Food and Drug Administration granted emergency use authorization for two highly effective vaccines, these sentiments helped shape the Foundation's [website](#) content and [webinar](#) where experts shared the latest information on COVID-19 vaccines.

EXPERIENCES WITH VIRTUAL CF CARE (TELEHEALTH)

Community Voice members supported the quick mobilization of CF care programs to deliver virtual care by participating in a national survey and interviews. Members shared their experiences of access and use of telehealth services, access and pivots to treatments and remote monitoring devices, financial concerns, and the interest of using telehealth long-term. Through this feedback, the Foundation gained insight into how telehealth can be adopted as a part of routine CF care and better support care programs, patients, and families.

Researchers from the CF Foundation, care centers, and the National Institutes of Health (NIH) examined topics such as mental health, access to routine care and medications, and overall health outcomes. These studies provided researchers the opportunity to quantify and better understand the pandemic's impact on both the CF and overall rare disease community.

CRUCIAL TOPICS IN 2020 • CONTINUED

COMMUNITIES OF COLOR

CF affects people of many different racial and ethnic backgrounds, although not all voices are equally represented in the Foundation's work. Hearing from diverse voices is critical to understanding the unique needs and perspectives of every person within the CF community. Communities of color have been shown to have poorer health outcomes and face increased burdens to access high quality care. Therefore, a **group** was developed to hear from people of different ethnic and racial backgrounds to seek **racial justice** and ensure all races and ethnicities are represented in research, care, and beyond. As part of the first phase of this effort, members shared their experiences and the major challenges regarding race and discrimination.

I OPTED INTO THE COMMUNITIES OF COLOR LIST BECAUSE AS A WOMAN OF COLOR WITH A SON WHO HAS CF, WE DESERVE TO BE HEARD AND SEEN. IT HAS BEEN A DIFFICULT TIME WORKING WITH MEDICAL PROFESSIONALS WHO DON'T BELIEVE THAT MY SON HAS CF.

I HOPE THAT THIS WORK WILL HELP RAISE AWARENESS THAT CF DOES NOT ONLY AFFECT ONE RACE AND MAKE IT SO THAT IF MY SON DECIDES TO HAVE A FAMILY, AND SHOULD THEY HAVE CF, THEY WILL BE TAKEN SERIOUSLY AND RECEIVE THE CARE THEY NEED.

 **Lathronia Jefferson**, Community Voice Member

As this work continues, the Foundation is focused on highlighting the experiences and perspectives of people of color with CF and their families through listening and transparency.

NONSENSE & RARE MUTATIONS

In addition to reaching people of color within the CF community, the Foundation is also focused partnering with people with CF who are not eligible or able to benefit from cystic fibrosis transmembrane conductance regulator (CFTR) modulator therapies. A separate opt-in opportunity was established for these individuals to ensure their voices are also being represented across CF research and care projects.

LOOKING AHEAD

AS AN ACTIVE MEMBER OF COMMUNITY VOICE FOR THE PAST FEW YEARS, I KNOW MY CONTRIBUTIONS HAVE BEEN A CRITICAL COMPONENT TOWARDS THE SEARCH FOR A CURE FOR ALL PEOPLE WITH CF.



IT HAS BEEN REWARDING TO WITNESS MY EXPERTISE AND EXPERIENCES AS A SPANISH SPEAKING PARENT OF A PERSON WITH CF BENEFIT RESEARCH, CARE, AND THE BROADER CF COMMUNITY.

 **Sylvia Mazuera**, Community Voice member

2020 marked six momentous years of Community Voice. This dynamic group of more than 1,300 people with CF and their family members have taken an active role in impacting programs, resources, and efforts that have helped shape the future for the CF community.

Looking ahead, we have planned our priorities to align with feedback from our [end-of-year survey](#) and the Foundation's long-term focus on cure, care, and community. Our priorities for 2021 include:

Grow and diversify
the membership of
Community Voice

Enhance the
recognition
and experience
of members

Amplify the
utilization
and impact of
Community Voice



**CYSTIC FIBROSIS
FOUNDATION®**

4550 Montgomery Avenue
Suite 1100N
Bethesda, MD 20814

1.800.FIGHT.CF
cff.org/CommunityVoice