Letter from the Editorial Board

Happy fall! We are proud to present the third edition of the Community Voice Newsletter -- chock-full of project results, highlights, blog posts, and new opportunities for participation.

Our impact as a group has been changing the way the Foundation, researchers, and clinicians approach projects, and we’re just getting started! In this edition, we’ll highlight all the areas where Community Voice members made an impact on the projects and studies being presented at the North American CF Conference (NACFC) this month. As you’ll see in the Feature Story, the community also helped determine which content is being livestreamed this year, which -- thanks to your requests -- will be more accessible than ever before. We hope you’ll join us in learning about the latest in CF research by watching the livestream sessions and the other sessions that will be archived after the conference.

Best,

The Community Voice Editorial Board

Feature Story:

Your Impact on the North American CF Conference

The 32nd annual North American CF Conference (NACFC) is happening in Denver on Oct 18-20, 2018. NACFC is the leading conference in North America for all disciplines of CF clinicians and basic scientists. It is also a place where your voice is heard throughout the sessions, plenaries, and abstract posters.

This year, Community Voice members chose the sessions they wanted to be livestreamed.
Based on feedback from the community, livestream registrants will also have access to the workshop and symposia presentations six weeks after the conference closes (as long as the presenter agrees). Additionally, the CF Foundation will be broadcasting three Facebook Live sessions after each plenary to connect the speakers to the Facebook viewers.

Visit the NACFC Watch Live page to read descriptions of the live-streamed sessions. You can register to watch them in real-time and access archived sessions.

Meet Melanie Abdelnour, an adult with CF who is a panelist for the third NACFC plenary entitled Partnering: The Oldest New Idea to Improve CF Care.

"I am most excited for the plenary to promote the importance of partnerships (co-production) between patients/families and their clinicians. It will not only explain why it’s so important but also ways we can improve our dynamics. As a person with CF, I'm thrilled about the promotion of this topic and honored to be a part of it."

A Look at Your Impact In...

CF Science

“It is really eye-opening to look at the input that Community Voice and other groups have given on what matters most to them. While clinicians and patients/families are often on the same page, this input really sharpens our focus on issues that matter most, and often gives us new ideas and insights on how we might be able to help. We are really lucky to have amazing resources that let us treat the whole person/family in ways that many other disease areas don’t. Working together with the entire CF community ensures that we are always pointed in the right direction."

Dr. Scott Donaldson
Chair CF Clinical Advisory Board, Professor of Medicine, Director, UNC Adult CF Center

Clinical Research Grants

For the first time this year, members of Community Voice helped review the Clinical Research Awards and Clinical Pilot and Feasibility Awards. As a result, the Foundation has decided to move forward with funding for six Pilot and Feasibility Awards and three Clinical Research Awards. Projects include research topics investigating CFRD, CFLD, CF-related gastrointestinal complications, and mental health interventions.
Infections Research Focus Group

The topic of infections was identified as the top priority by over 1,900 community members during the research prioritization project. Following this feedback, the Foundation developed the **Infections Research Initiative** to improve detection, diagnosis, treatment, and outcomes of infections for people with CF. Several of you joined in on a focus group that helped develop the name, mission statement, and focus areas for the initiative. The specific topics you helped identify were:

- Improving detection and diagnosis
- Understanding CF microorganisms
- Developing new treatments
- Optimizing current treatments
- Evaluating long-term antimicrobial use
- The future of CF infection

CF Care

GI Wellness Study

Community Voice members were instrumental in helping the Foundation and the Therapeutics Development Network (TDN) choose a questionnaire for an upcoming gastrointestinal wellness study designed to gain a better understanding of GI symptoms that people with CF experience on a daily basis. Survey participants gave input on which questionnaire would be the most beneficial and easiest to complete.

Colorectal Cancer Focus Group

Several of you helped inform the new **Colorectal Cancer and CF** content section on cff.org. Your experience and insights helped the Foundation to better understand that:

- General awareness of colorectal cancer is an issue
- Coordination of care is important, including who to talk to about getting a colonoscopy and facilitating communication between your endoscopist and CF care team
- The need to help GI specialists understand the implications of CF and CFRD as it relates to colonoscopy preparation and subsequent screening
  - A one-pager has been developed about preparing for a colonoscopy when you have CF

Pain Management Survey

In an effort to learn more about pain management in the CF community, researchers at Johns Hopkins gathered insights from Community Voice and other CF community members about their
experiences with pain. Two abstracts were developed for NACFC from the results that offer suggestions for how to address this topic. Both acknowledge Community Voice’s participation. Key findings include:

- Providers vastly underestimate the percentage of patients who experience CF-related pain and pain as a symptom of CF. (Abstract: Provider and Patient Attitudes Towards CF Pain Management)
- Four out of five people with CF who’ve had a lung transplant experience pain. The most common types of pain reported by transplant recipients with CF were non-sinus related headaches, lower back pain, acid reflux, sinus pain, abdominal pain, and joint pain. (Abstract: Pain in Post-Lung Transplant Individuals with Cystic Fibrosis)

**Patient Experience of Care Survey**

Based on feedback from Community Voice members, the Patient Experience of Care Survey will now include 22 fewer questions than the original, ultimately allowing the survey to be completed in less time. (Abstract: Revising the CF Patient and Family Experience of Care Survey)

**PSDC Communication Study**

In late 2017, Community Voice members provided insights into their communication experiences with their care teams. Based on those results and other research, the Foundation has partnered with the Academy on Communication in Healthcare to develop a pilot program for health care providers to learn key partnership skills, including trust-building, creating an open dialogue, active listening, empathy, negotiating agendas, and partnering toward an agreed-upon treatment plan. (Abstract: Identifying Communication Preferences Among Individuals with CF, Families and CF Clinicians)

**Other abstracts that reference Community Voice:**

- "I think everybody needs to hear that it’s worth it": Using patient and caregiver narratives to enhance decision making about advanced-stage care among CF adults
- Assessing Practices, Beliefs and Attitudes about Palliative Care among People with CF, their Caregivers, and Clinicians: Results of Qualitative Thematic Analysis

**Community Program**

**Community Impact Grants**

Congratulations to the following programs, which feature involvement from Community Voice members and were recently awarded an Impact Grant. Impact Grants provide up to $10,000 to individuals or organizations that
are helping to benefit the CF community. Check out the other programs who were awarded this year.

- CF Yogi
- CFReSHC
- Developing Resources for Young Professionals with Cystic Fibrosis

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## Community Tips & Tricks

In the last edition, you all helped share tips and tricks about living with CF. Check out these new tips from three of your fellow Community Voice members. Please note that these tips are not intended to be medical advice and everyone's experience with CF is different.

**Tip #1**

 Surprise your loved one with a clean treatment area, encouraging and loving notes, or fun "treats" for them to find and remember they are loved and their work is appreciated.

- Julie R., spouse of a person with CF; runner, stand up paddle boarder, and indoor rock climber.

**Tip #2**

 We make big batches of guacamole from scratch. My child helps mash together three magic ingredients: avocado, fresh-squeezed lemon juice to taste, and sea salt. We serve it with chips or on buttered toast.

- Jillian D., parent of a child with CF; fun fact: her family traveled to 28 states and visited 6 national parks last summer.

**Tip #3**

 Sleep can sometimes be an issue for me. Avoiding screen time at least 30 minutes before bed helps me fall asleep.

- Emily G., person with CF; likes to go to the beach with Bella, her Italian Mastiff.

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## Member Spotlight

We would like to introduce you to Steven Hall, an adult with CF who joined Community Voice in July, and owner of a dog, Lukas, who he adopted from South Korea!

**Tell us about yourself!**
I’m almost 30 years old and grew up near Princeton, N.J., with my two older brothers – neither of whom have CF. After earning my B.A. from the University of Maryland, I moved to Washington, D.C., where I now work as a financial advisor specializing in helping families with children who have special needs. I met my wife in 2014 and we got married a few weeks ago on Sept. 1. We live in Northern Virginia with our dog, and are very involved in local CF Foundation chapter events.

What do you like to do in your free time?

I grew up playing every sport imaginable and I never had a season off, which is something I really miss. Luckily, my wife and I love to be active. Whether it’s hiking with the dog, playing tennis, or kayaking, we really try to get outside and enjoy outdoor activities.

Why is it important for you to get involved in the CF Community?

For a long time, I was quiet about having CF and very few people knew I even had it. My wife really motivated me to become more involved. She felt like I had a lot to contribute and helped me to embrace the fact that I could make a difference -- not only for the future of the disease, but for those who, like me, are dealing with adversity every day. I wanted to find a way to be impactful on more than my own life.

Stay tuned to learn more about your fellow Community Voice members with each issue!

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In Other Community Voice News

CF Community Blog
Check out these recent blog posts by other Community Voice members! Community Voice currently has 75 members who have written 151 posts since the CF Community Blog launched!

- Finding My CF Mom Tribe - Rachael Havey
- Demystifying the Colonoscopy - Amy Braid
- Remembering Claire Wineland - Katherine Russell-Sponaugle

Want to contribute to the CF Community Blog? Fill out this questionnaire.

Last Newsletter Edition
Need to catch up? Check out the Spring 2018 Edition of the Community Voice Newsletter.

Other Ways to Get Involved

- Enjoy being a member of Community Voice? Find more ways to get involved on a national and local level.
- Join Research Voice! Research Voice is a subgroup of Community Voice designed to embed the voice of the community into research projects. Members are getting involved in
all aspects of research, including reviewing study protocols, reviewing study safety, and disseminating lay summaries of study results.

**Help Spread the Word about Community Voice - Let's Get to 1,000 members!**

The more people who sign up and share their perspectives, the stronger our impact will be. Help the group grow to 1,000 voices strong by 2019! If you know a person with CF or a family member of a person with CF, invite them to join Community Voice at [cff.org/CommunityVoice](http://cff.org/CommunityVoice).