

# **CF Adult Advisory Council: 2018-2019 Term Year in Review**



# A Letter From the Chair

**“The charge of the CF Adult Advisory Council is to convey the hopes, needs and aspirations of the CF adult community.”**



Throughout the 2018-2019 term year, the CF Adult Advisory Council (AAC) has continued to contribute invaluable insight and guidance on many different initiatives to further help the Foundation provide people with cystic fibrosis the ability to live full and productive lives.

The charge of the Council is to convey the hopes, needs and aspirations of the CF adult community. Our group gathers insights not only from personal experience, but collects input from their own communities to address the unique challenges and circumstances for adults living with CF.

The AAC has had another incredible year, working with many teams across the Foundation on a wide variety of topics. We formalized our recruitment process through Community Voice and after a highly competitive application process, brought on four wonderful new members.

The AAC Alumni group, which now has 12 members, has taken shape and is continuing to explore new and innovative ways to keep the growing group engaged in the work of the AAC and the CF Foundation.

In 2018, the Council participated in the third year of Impact Grant reviews. After much discussion and review, eight programs were selected to receive funding, in addition to the renewal of three programs chosen in 2017.

As you look through all that was accomplished during the 2018-2019 term, you can find more information about all of these projects by clicking on highlighted words and photos.

I am so proud of the work this group has accomplished this past year and can't wait to see what we achieve in the next year!

KC White

Chair

CF Adult Advisory Council

# Members

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Maria Bellefeuille  
Gurnee, Ill.



Marieliz Landa  
Chicago, Ill.



David Davison  
Council Bluffs, Iowa



James Lawlor  
Huntsville, Ala.



Sandy Driste  
Minneapolis, Minn.



Molly Pam  
New York, N.Y.



Kristin Dunn, Vice Chair  
Basking Ridge, N.J.



Chad Riedy  
Alexandria, Va.



Brandon Erhart  
Grand Rapids, Mich.



Sabrina Walker  
San Francisco, Ca.



Cheriz Kunkel  
Peoria, Ill.



KC White, Chair  
Chagrin Falls, Ohio

# AAC Projects

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One of the main roles of the Council is to advise CF Foundation staff on current topics and initiatives. During the 2018-2019 term, the AAC met with teams from almost every department at the CF Foundation and helped guide staff on many critical projects.

## Infections Initiative and ResearchCon

One of the most common types of projects the AAC works on is providing guidance and feedback on new or expanding community programs. Members give early feedback on the project and provide guidance for how to move forward. They also ensure that the program is both something that the CF community actually wants or needs and is structured in a way that makes sense. Meeting with the AAC often occurs early in the development process before being discussed with other stakeholders or Community Voice members for broader feedback.

In 2018, the AAC learned about the new Infections Research Initiative and were part of early discussions of what would eventually be called ResearchCon. The group consulted on the general concept of a research-based virtual event and if the Infections Research Initiative might be a good fit for the first topic. Many members went on to join the working group or to present or facilitate during the event.

## Strategic Planning

Another major topic for the 2018-2019 term was the Cystic Fibrosis Foundation's strategic planning process. Through multiple calls, the Council has weighed in on all categories of the strategic planning process and for areas that are especially important to people living with cystic fibrosis. They will continue to contribute to the process as it progresses throughout 2019 and ensure that the plan adequately reflects the needs of people with cystic fibrosis and their families.

## NACFC

An ongoing topic for the Adult Advisory Council is the annual North American Cystic Fibrosis Conference (NACFC). The AAC consults on ways to better engage virtual participants with the conference and other areas for improvement.

## Alumni Group

The Adult Advisory Council Alumni group was created in 2017. In 2018, the group expanded to include 12 members in total. While this group is still new, they played a role in a number of projects over the last year. Several members served as part of the review committee for the new Community Support Grants. Others provided feedback to help develop new community resources for Compass and helped facilitate informational calls for teenagers with cystic fibrosis. Members are also participating in a new onboarding initiative with new CFF employees to help them better understand the disease and feel connected to our mission.

We are excited to continue expanding the role of this group as it keeps growing in size!

# Impact Grants

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[The 2018 Impact Grant recipients](#) are bettering the lives of people in the CF community through a range of programs from exercise to life coaching and professional development. In addition to the eight new grants in 2018, three 2017 Impact Grant recipients had their projects renewed for one year.

Below you will find four of the eight 2018 Impact Grant recipients.

## CF Yogi

CF Yogi is a virtual yoga studio with weekly livestreamed yoga classes led by instructors who have firsthand knowledge of yoga and CF and its value as a self-empowering tool for those living with the disease. Classes are open to adults and kids with CF, parents and caregivers, spouses, families, and friends.



## Cystic Fibrosis Reproductive & Sexual Health Collaborative

The Cystic Fibrosis Reproductive & Sexual Health Collaborative (CFReSHC) invites women with CF to partner with health care providers and researchers to help shape the future of CF research on sexual and reproductive health issues. CFReSHC holds monthly virtual meetings for women with CF to share their experiences, help identify knowledge gaps, and formulate key research questions to inform patient-centered research projects.

## Breathe for Britt Run Club

Breathe for Britt Run Club is an online community for people with CF and family members that promotes the benefits of running and walking, and provides access to resources to track and achieve measurable fitness goals, such as completing a 5K. The program will launch in 2019 and will include a personalized 12-week training program, access to a running coach, and fitness tracker technology.

## 3rd Street Society: Cystic Fibrosis Surf Clinics

The 3rd Street Society's Cystic Fibrosis Surf Clinics, based in Folly Beach, S.C., contribute to the health and happiness of people with CF by providing a half day of one-on-one surfing instruction for people with CF and two of their family members or friends in a safe and fun environment.



# The Legacy of the AAC

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Members of the AAC have played a major role in the inclusion of people with cystic fibrosis and their families in the work of the CF Foundation. In addition to providing feedback on countless Foundation initiatives and topics, the Council identified various needs within the CF community and came up with innovative ways to connect people with CF and their families. Many members also continue to be involved in these programs today.

## Peer-to-Peer Mentoring Program

In May 2016, a pilot peer mentoring program for adults with CF, now called CF Peer Connect, was launched. The idea was generated from the AAC and was developed with significant community input via the Mentoring Advisory Committee. CF Peer Connect aims to leverage the expertise of the CF community to support peers who face similar life transitions and challenges while managing life with CF.

[CF Peer Connect](#) is now available for all people with cystic fibrosis and their family members age 16 and older.

## CFPEERCONNECT

## Virtual Events

In October of 2016, AAC members Marissa Benchea and KC White led the first ever [BreatheCon](#), a virtual event where adults with CF could connect, learn, share and inspire each other. The idea for this type of space came directly from the Council and through their efforts, expanded to six virtual events in 2018, three of which were open to people with CF and their family members. Many AAC members have participated in virtual events work groups and as panelists, facilitators, and attendees since the inception.



## Impact Grants

The [Impact Grants program](#) began in 2016 and grew out of an idea from the AAC. The program provides support to individuals and nonprofit organizations with projects that benefit people with CF and their families. Impact Grants award up to \$10,000 per project and are renewable for an additional year. The AAC continues to be actively involved in the Impact Grant program, by serving as the review committee each year.

