



# **CF Adult Advisory Council: 2017-2018 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 2017-2018 term year, the CF Adult Advisory Council (AAC) has continued to contribute invaluable insight and guidance on many different initiatives to help the Cystic Fibrosis 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. AAC members not only gather insights from personal experience but also collect input from our own communities to address the unique challenges and circumstances for adults living with CF.

The AAC has seen a lot of growth in the past year! We saw an increase in the number of requests for AAC guidance and reached more departments across the Foundation than ever before. The high demand for input from Council members, in addition to the need to maintain relationships with AAC members after their terms have ended, paved the way for us to create the AAC Alumni Group. This group has been an incredible resource, allowing us to bring in more voices to critical projects and to expand the flexibility of scheduling ad hoc meetings.

In 2017, the Council also participated in the second year of Impact Grant reviews. After much discussion and review, four strong programs were selected to receive funding, in addition to the renewal of all seven programs chosen in 2016.

As you look through all that was accomplished during the 2017-2018 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



Ashley Ballou-Bonnema  
Sioux Falls, S.D.



Cheriz Kunkel  
Peoria, Ill.



Maria Bellefeuille  
Gurnee, Ill.



Heather McCoy  
Sumter, S.C.



Marissa Benchea  
Nashville, Tenn.



Chad Riedy  
Alexandria, Va.



David Davison  
Council Bluffs, Iowa



Kyle Shiel  
Boston



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



Sabrina Walker  
San Francisco



Brandon Erhart  
Grand Rapids, Mich.



KC White, Chair  
Chagrin Falls, Ohio

# AAC Projects

One of the main roles of the Council is to advise CF Foundation staff on current topics and initiatives. During the 2017-2018 term, the AAC met with teams from almost every department at the CF Foundation and helped guide staff on many critical projects.

## Community Program Development

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 on 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 2017, several programs that were created from previous AAC feedback were piloted and expanded, all with the guidance and participation of Council members. Members took active roles in the CF Peer Connect pilot program and continue to participate in the program today as both mentors and peers. Virtual Events expanded this year to include family members in select events. Members of the Council were consulted in the early phases of this expansion to help guide the team to meet the needs of the CF community.

## Improving CF Care and Research

Another area that the Council is highly involved in is the research and clinical care space. The Council meets with members from our research teams to discuss the best way to talk about sensitive topics, include members of the community in research, and provide general feedback on projects.

In addition to assisting with the expansion of community-focused programs, the Council met with teams across the CF Foundation to provide guidance on scientific communications, chapter engagement with the CF community, care center relationships, clinical trial expansion, and many more projects.

## Alumni Group Creation

The Adult Advisory Council Alumni group was created in 2017. The mission of the Alumni Group is to keep former AAC members connected to the CF Foundation by providing them with an ongoing opportunity to participate in Foundation projects and give feedback on various Foundation activities. Participation in the Alumni Group is entirely optional, so members can contribute as they choose. Led by co-chairs Stacy Carmona and Jennifer Bleacher, we look forward to growing this group both in size and in the number of opportunities for members to connect with the CF Foundation and one another.

# Impact Grants

In 2016, the AAC helped review the first round of [Impact Grants](#), which were given out to seven inspiring and innovative groups working to meet the needs of people with CF and their families. The programs have been so successful that they are all renewing for an additional year. In 2017, the Council reviewed 15 applications and the [four programs](#) featured below were selected for funding.

## The Cody Dieruf Benefit Foundation: Retreat for Mothers of Children With CF

The Cody Dieruf Foundation's *We Walk Together* program is a three-day retreat for mothers of children with CF that live in Montana, Idaho, and across the country. Retreats offer a safe space for mothers who share a connection through CF to come together for support, education, and community.



## CF Society, Inc.: CFS Gazette Newsletter

The CF Society's CFS Gazette Newsletter is written for people with CF of all ages and their families. The Gazette offers news about the latest medical advances and clinical trials, CF-friendly recipes, special profiles featuring community members, columns written by experts in the CF field, and personal stories. Additionally, the Gazette contains cartoons, jokes, and games as part of its mission to provide people with CF and their families with both information and entertainment, as it emphasizes the old adage that sometimes laughter is the best medicine.

## Kid Logistics

Kid Logistics, Inc. is a nonprofit organization dedicated to helping kids with CF in Mississippi live healthier, happier lives through exercise and activity. As part of its *Kids Busy Living* program, the organization funds participation in extracurricular activities such as summer camps and sports programs. They also provide educational tools for program providers about the special needs of children with CF and provide products, such as hand sanitizer and tissues, to aid in infection control.

## Meghan's Light, Inc.: 65 Wellness Wishes

Meghan's Light 65 Wellness Wishes grants 65 health-focused awards for wellness memberships and activities in and outside the hospital. Recipients are children and adults with CF treated at Boston Children's Hospital, with a percentage reserved for Boston Children's patients living in Western Massachusetts. The project honors Meghan's lifelong passion for fitness and supports recipients in incorporating wellness and fitness into their own lives.



# The Legacy of the AAC

Members of the AAC have played a major role in the inclusion of people with CF and their families in the work of the CF Foundation. In addition to providing feedback on countless Foundation initiatives and topics, the Council has identified various needs within the CF community and come 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 facing similar life transitions and challenges while managing life with CF.

In 2018, [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 came directly from the Council, and through their efforts, it was 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 event's inception.

**CFfamilyCON**  
CYSTIC FIBROSIS FOUNDATION

**BREATHECON**  
CYSTIC FIBROSIS FOUNDATION

**CFminiCON**  
CYSTIC FIBROSIS FOUNDATION

## 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.



# 2017 Addendum

*We are adapting the structure of our annual reports to reflect each term instead of the calendar year. This addendum covers the missing six-month period between the 2016 Annual Report and the beginning of the 2017 term, which is from January-May 2017.*

## January - May 2017 Projects

In the first half of 2017, the AAC participated in a variety of projects including assisting with the launch of Community Voice, looking at the shifting corporate culture at the Foundation, providing feedback on a medical animations project, and overall expansion of AAC-initiated projects.

## 2017 AAC Members

*The members listed below were members of the AAC from January-May 2017 and contributed their time and talents for projects during this time.*



Stacy Carmona



Andrew Corcoran



Andy Lipman



David Cobb



Ilene Hollin



Katharine Scrivener

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## Looking Ahead

We are looking forward to a productive and impactful 2018-2019 term. In the spring of 2018, we began the onboarding process for four new AAC members.

Members of the AAC will soon begin the review process for the 2018 Impact Grant applications and continue to work with the Impact Grants staff members to help expand the program and support organizations who are serving the CF community.



For more information about or to join [Community Voice](#), please visit [cff.org](http://cff.org). All AAC members are recruited from Community Voice annually.



If you'd like to learn more about the AAC or have any questions, please email us at [communitypartnerships@cff.org](mailto:communitypartnerships@cff.org).