

CF Adult Advisory Council: 2020-2021 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 2020-2021 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.

In order for the AAC to be successful we need to ensure that our membership is representative of the many diverse experiences within our community. This includes hearing from members who can not benefit from current modulators, people of color, men, those who have gone through a lung transplant, and many other experiences. We rely on the diverse voices on the AAC to give their own perspective as well as help us understand the needs of the broader CF community.

The AAC has had another incredible year, working with many teams across the Foundation on a wide variety of topics. This report will offer insight into the types of work that the AAC contributed to this year, but the impact of their work goes far beyond what can be conveyed here.

The AAC Alumni group continues to explore new and innovative ways to keep former members engaged in the work of the AAC and the CF Foundation.

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



Gabriella Balasa
Richmond, VA



Aimee Lecointre
Salt Lake City, UT



Edward Canda
Lawrence, KS



Somer Love
Midvale, UT



Kristin Dunn, Vice Chair
Basking Ridge, NJ



Lydia Sand
Omaha, NE



Tara Goodwin
Houston, TX



Dan Schulke
Washington, D.C.



Brad Johns
Mendenhall, MS



Betsy Sullivan
San Antonio, TX.



Katie Kirby
St. Louis, MO



KC White, Chair
Chagrin Falls, OH

*In 2020-2021, Alumni Group member Linda Bowman served as a special advisor to the Council

AAC Projects

One of the main roles of the Adult Advisory Council is to advise CF Foundation staff on current topics and initiatives. During the 2020-2021 term, the AAC met with teams from across the CF Foundation and helped guide staff on many critical projects. Many of the projects the Council work on are confidential, so below represent just a small sample of the work accomplished this year.

COVID-19 Response

COVID-19 has continued to be a major topic for the AAC during the 2020-2021 term. Early in 2020, the AAC hosted the Happiness Hour, which was the first of what became many CF Foundation sponsored virtual events to bring the CF community together. Learnings from this event greatly informed the development of other events that occurred throughout 2020 and into 2021. Members of the Council also participated in several of these events as speakers, moderators, and attendees.

Throughout the term year, members advised CF Foundation staff on various communications strategies, reviewed early drafts of resources, and provided feedback on other sensitive topics relating to COVID-19.

Community Outreach

Another major topic for the 2020-2021 term was advising Foundation staff on strategies to expand impact and reach new members of the CF community. As programs at the Foundation continue to evolve, members of the Council informed business plans and strategy behind new outreach methods and ways to better serve the broader CF community.

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 members of the CF community with the conference and other areas for improvement. In 2020, they specifically provided insights around the first ever all-virtual NACFC and guidance on how to include people with CF and their families in this event.

Leadership

Each year, the AAC meets with leadership from across the CF Foundation. These meetings are a combination of updates from leadership, as well as discussion around pressing issues in that field. Members meet with leaders from across the Foundation, including the President and CEO Dr. Boyle, as well as heads of Research, Care, and Advocacy. Representatives from across the Foundation also meet with the Council regularly on topics relating to research, community support, fundraising, and other projects as needed.

AAC Alumni

The Adult Advisory Council Alumni group was created in 2017. In 2020, the group included 23 former AAC members. This group of volunteers supports the work of the AAC by participating in projects when the Council has a full calendar, providing additional voices and perspectives on complex projects, and staying engaged in various work groups. We are excited to continue expanding the role of this group as it keeps growing in size and influence!

CFF Staff Orientation

Several members of the Alumni group make up a small working group to participate in the CF Foundation staff orientation process. As part of the onboarding process, new staff hear directly from a person living with cystic fibrosis and have the opportunity to ask questions. This new presentation has been highly rated from staff and allows new hires to feel connected to our mission from the beginning of their time with the Foundation. Alumni speakers have been an incredible addition to our onboarding process!

Community Support Grants Review

In addition to the Impact Grants, which are reviewed by members of the current AAC, the Foundation also offers Community Support Grants. Community Support Grants provide additional support to previous Impact Grant recipients who are continuing to innovate how they engage and empower people with CF and their families. The Community Support Grant review committee is recruited from the AAC Alumni Group, who then evaluate programs to ensure a commitment to demonstrating a high standard of service as they work to scale their reach and impact.

Members

- Ashley Ballou-Bonnema
- Maria Bellefeuille
- Marissa Benchea
- Jennifer Bleecher
- Linda Bowman
- Stacy Carmona
- David Cobb
- David Davison
- Sandy Driste
- Brandon Erhart
- Joan Finnegan Brooks
- Ilene Hollin
- Cheriz Kunkel
- Marieliz Landa
- James Lawlor
- Andy Lipman
- Heather McCoy
- Josh Mogren
- Molly Pam
- Chad Riedy
- Katharine Scrivener
- Kyle Shiel
- Sabrina Walker

The Legacy of the AAC

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 Community Conferences

In October of 2016, AAC members 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, has expanded to a variety of annual conferences including BreatheCon, ResearchCon, FamilyCon, and MiniCon:Transplant. 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.

