CF Adult Advisory Council

2016 in Review
Throughout 2016, the CF Adult Advisory Council has continued to contribute important 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 CF Adult Advisory 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 Adult Advisory Council has seen many big ideas come to fruition in 2016! The first ever BreatheCon was held this year, which was an idea spurred from the Council. The Peer to Peer Mentoring program, another initiative from the council, also began piloting in care centers around the country.

The Council also took on new projects and challenges, including the daunting task of reviewing the first ever round of Impact Grant applications.

As you look through all we accomplished in 2016, 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 2017!

Sincerely,

KC White
Chair, CF Adult Advisory Council
Board of Trustees Officer
In 2016, the Cystic Fibrosis Foundation launched the **Impact Grant Program**. The Impact Grant Program provides up to $10,000 per year to individuals or organizations that benefit the CF community.

The **CF Adult Advisory Council** took part in the Impact Grant program by evaluating over 20 applications.

### 2016 Impact Grant Awarded Programs

<table>
<thead>
<tr>
<th>Title and Applicant</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cystic Fibrosis Lifestyle Foundation</td>
<td>Program to help people incorporate exercise-based activities into their daily lives on a national level</td>
</tr>
<tr>
<td>Miles for CF – Project Breathe Strong</td>
<td>Program to help people incorporate exercise-based activities into their daily lives on a regional level</td>
</tr>
<tr>
<td>United States Adult CF Association (USACFA) - CF Roundtable</td>
<td>A quarterly paper and web-based publication for and by adults with CF to facilitate exchange of medical and non-medical CF information and provide a network for communication</td>
</tr>
<tr>
<td>Project CF Spouse</td>
<td>Creation of a non-profit organization to serve as an information hub and support group for spouses of people with CF</td>
</tr>
<tr>
<td>Breathe Bravely – sINgSPIRE</td>
<td>10-week skype-based program focused on singing to address physical and psychological aspects of CF</td>
</tr>
<tr>
<td>Attain Health</td>
<td>Health coaching and personal training provided over the web</td>
</tr>
<tr>
<td>Continuing Education for Caregivers/Individuals with CF</td>
<td>Web-based program for educational workshops to improve knowledge of CF and self-management skills</td>
</tr>
</tbody>
</table>
A group of adults with CF, with support from the CF Foundation, decided to create a space for the first time where adults in the community could connect, learn, share and inspire each other. **BreatheCon**, in its inaugural year, served as that space, a space that revolved around life as an adult with CF -- for adults with CF, designed and delivered by adults with CF.

Fourteen individuals with CF, including council members Marissa Benchea, Stacy Carmona, Kristin Dunn, Ilene Hollin, and KC White, and several previous AAC members, participated on the work group. The work group was split into two focus areas: Outreach and Programming and Content. Conference attendance and participation was driven solely by the networks and contacts of adults with CF and the agenda was also created by the work group. Participants enjoyed two keynote presentations, joined small group video breakout sessions, participated in mindfulness-based stress relief and a yoga class and chatted one-on-one and in groups. All content was prepared and delivered by adults with CF, including the council members who served on the work group and Ashley Ballou-Bonnema, Katharine Scrivener, and Kyle Shiel serving as breakout group facilitators.

**BreatheCon** was considered a huge success. 80% of attendees who participated in the survey rated BreatheCon as a ‘10’ and would recommend the event to others in the future. We will continue partnering with the community to develop spaces like BreatheCon for people in the CF community to connect.
The CF Adult Advisory Council continues to be one of the most beneficial sounding boards for the Foundation on new developments. Members of the Council are part of a variety of projects including offering opinions and feedback on the Foundation website, resources, and videos. They also regularly contribute to the Foundation’s blog. In 2016, the CF Foundation began the Speaker Series and Council member Stacy Carmona was invited to share her story with Foundation employees.

Building a Better Online Community
By Andy Lipman | May 18, 2016
These days when I post in any CF group, I read my posts several times over, making sure that I’m not incentivizing bullies to jump all over them. It’s a shame that I have to waste hours each week concerning myself with how someone will interpret something I write.
Topics: Social Life and Relationships

How Infertile Men With CF Can Still Have Biological Kids
By David Cobb | June 13, 2016
After being told at the age of 14 that I was probably infertile, the day finally came when this news mattered to me. But with IVF and the support of our church, my wife and I are now the proud parents of three biological children.
Topics: Fertility and Reproductive Health

We Are Ready to Make Our Voices Heard
By KC White | November 30, 2016
A top priority for the next administration and Congress is health care reform. As an adult living with cystic fibrosis, I’ve been wondering what this will mean for me, our community and our ability to access high-quality, affordable care.
Topics: Get Involved, Advocacy

Speaker Series: Connecting Foundation Employees to CF Community Members
By Kelsey Fredkin | May 6, 2016
Through a new Speaker Series, the Foundation invites people with cystic fibrosis and their families to the national office to share their stories and help Foundation employees better connect with members of our community.
Peer to Peer Mentoring

Peer to Peer Mentoring for adults with cystic fibrosis is a formalized, subject-based peer support program that originated as an idea from the AAC. In this program, Peer Mentors use their knowledge, experiences, and compassion to mentor Peers who seek to connect with someone who has experience in a particular life management area. The overall goal of the Peer to Peer Mentoring program is to leverage the expertise in the community to foster happier, healthier lives for people living with CF.

The pilot Peer to Peer Mentoring program was launched in 2016 with the recruitment of Peer Mentors from 12 pilot care centers followed by the recruitment of Peers through the care centers and via a one-time email blast. To date, 53 Peers have been matched with Mentors.

The pilot phase of this program will continue through May 2017, with a goal to make the program accessible to adults with CF nationally by the end of 2017. A Mentoring Advisory Group, made up of people with CF and their families, care team members, and CF Foundation staff, continues to provide input and strategic direction on a quarterly basis.
In 2016, the Foundation hosted the third virtual CF adult panel discussion at the Volunteer Leadership Conference in March. Andy Lipman moderated an open discussion with two CF adult panelists, including council member Katharine Scrivener via video. During the dialogue, panelists shared their perspectives on living with CF, navigating personal relationships such as dating and marriage, and continuing to embrace life in spite of their disease.

A total of 338 people watched the online streaming and there were over 500 people in the audience.

Click here to watch recordings from VLC 2016.

Each year, the Alex Award is presented at VLC to a person with CF who is a role model to others with the disease and embraces perseverance, showing unflagging courage in the face of this challenging disease. In 2016, council member Andy Lipman was the Alex Award recipient.
Also at the 2016 North American Cystic Fibrosis Conference, adults with CF and their families participated in the CF Foundation’s first Facebook live community sessions.

Chad Riedy and council member Kristin Dunn participated on the CF Foundation Community Connections and Partnerships session, which highlighted explore Partnerships for Sustaining Daily Care, the CF Adult and Family Advisors Group, Peer to Peer Mentoring, and BreatheCon.

View all of the Community Sessions from NACFC here.

For the first time at the North American Cystic Fibrosis Conference, adults with CF were featured in a plenary session. Brandon Erhart and council member Kristin Dunn participated in a panel discussion on participating in clinical trials during Plenary 2 on Clinical Research: A Worldwide CF Community Effort.

View all plenary sessions here.

9,558 Views, 347 reactions, 56 shares, 136 comments

Thank u for expanding and changing the way you speak about CF #NoLifeExpectancyJustLife

People like Kristin living with CF and parents of people with CF who serve either on their local center’s advisory or on an AFA are contributing not only to the CF community but also to their own mental wellness. Like Kristen said, it’s empowering.

1 <3 CF Adults! So thankful for all of you blazing this trail for the younger generations. So much hope in our CF Community!
**CF Adult and Family Advisors (AFA)**

The CF Adult and Family Advisors (AFA) are a group of people within the CF community (including parents, caretakers, spouses, siblings and people with CF) who are interested in getting involved with the Foundation to provide unique perspectives about CF care, research, and quality of life. Those who are interested in joining are able to fill out a comprehensive survey discussing their fields of interests, overall goals, specific strengths, and available time commitments.

Almost 100 new members joined the AFA in 2016! As part of an initiative for the Volunteer Leadership Council, council members Marissa Benchea, Kristin Dunn, Andy Lipman, Katharine Scrivener, and KC White participated in a peer to peer recruitment activity and helped spread the word about the exciting work of the AFA.

Future Adult Advisory Council members will be selected through their AFA applications and profiles.

---

**New AAC Members**

In 2016, we welcomed the following new members to the council:

Andrew Corcoran  
Ashely Ballou-Bonnema  
Heather McCoy  
Kyle Shiel
Looking Forward to 2017!

Celebrating 2016 on our holiday party call and looking forward to another great year in 2017!