

# Virtual Peer Support for People With Cystic Fibrosis and Their Family Members: A Program Evaluation

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## Abstract

We sought to evaluate the feasibility, acceptability, and benefits of a virtual one-to-one peer support program for people with cystic fibrosis and their family members through a retrospective program evaluation. This peer support program was developed in collaboration with patients, health care providers, and CF Foundation program staff. Mentees were paired with a trained peer mentor for 3-month mentoring via video, phone, email, or text. We found that the peer support program was feasible and acceptable. Success factors include a range of positive benefits including practical support as well as social and emotional support. Two-thirds of mentees reported at least 4 different benefits. Mentors reported multiple benefits after providing support through mentoring. Our program evaluation demonstrates that virtual peer support based on informal sharing of life experiences is an achievable way to provide social support and enhance health and well-being in chronic disease management.

## Keywords

behavioral health, caregiving, quality improvement, quality of life, respiratory care

## Introduction

Cystic fibrosis (CF) is a rare, genetic disease that affects multiple organs and leads to progressive respiratory failure and shortened life span. Life expectancy has improved dramatically due to new therapies, and the number of adults with CF now accounts for 56.0% of the CF population, up from 39.7% in 2003 (1). The increasing adult population is marrying, having children, and receiving college degrees in greater numbers. Despite gains in life expectancy and life milestones, CF can still impact many aspects of daily life and the treatment burden remains high, requiring several hours of treatments per day to minimize complications and loss of lung function. In addition to living with a chronic illness, people with CF have the added challenge that infection prevention and control guidelines recommend no direct contact between patients, in order to reduce the possibility of transmitting harmful bacteria (2). Managing a rare chronic illness that has a high treatment burden and limits in-person contact with peers presents myriad challenges to patients and their families. Parents, spouses, and other caregivers of people with CF also face challenges as they support a loved one through treatment regimens, clinic visits, hospitalizations, and managing daily life.

Children and adults with chronic illnesses, as well as parent caregivers, are at increased risk for psychological difficulties (3). A multinational study across 9 countries, including the United States, measured symptoms of depression and anxiety in over 6000 adolescents and adults with CF and 4200 parent caregivers. Both individuals with CF and parents had a prevalence of psychological distress 2 to 3 times higher than that reported in community samples. Social networks and peer support can have positive effects on physical, mental, and social health through improved coping mechanisms such as problem-solving, access to information, and perceived control. These coping resources can act as a buffer during times of stress (4). Peer support is a form of social support that involves sharing of experiences and information between individuals with similar

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circumstances in a nonhierarchical relationship (5) and allows patients and family members to discuss complex health challenges that others in their social network may not understand. Studies have highlighted the positive impact of peer-to-peer support for individuals with chronic or complex disease (6–10) as well as for parents of children with special health care needs (11,12).

Social support has been associated with fewer mental and physical health symptoms among adults with CF in a single center study (13). Online forums (14) and informal peer support can be a positive experience (15) and indicate that interest in peer support is not limited to local areas. Peer support can provide 4 key functions to people with chronic disease: assistance in applying disease management plans, emotional and social support, and on-demand support (16). Parents of children with disabilities have described the sense of isolation when others cannot understand their life and that shared experience was the necessary component of peer support (17). This is true as well in the CF community, where people face isolation and hours of daily treatments.

At the behest of adults with CF, we sought a new way to engender connecting with and learning from others with the shared experience of living with CF. We codeveloped a CF-specific national virtual peer support program to help individuals feel less alone and more supported. We describe the structure of this program and the reported benefits for participants.

## Methods

### *Development of CF-Specific Peer Mentoring Program*

**Patient and public involvement.** In 2015, adults with CF on a 12-member Cystic Fibrosis Foundation advisory council advocated for a program to enable people with CF to support their peers through mentorship and experience-sharing in a format that would allow more meaningful connections than social media can provide (18). In response, the Cystic Fibrosis Foundation worked with a multidisciplinary committee of adults with CF and CF care team members to develop a formal peer support program (19). Patients and care providers continued to act in an advisory role throughout the pilot implementation and evaluation. Family members of people with CF contributed to the development of the program expansion that would include parents and spouses/partners.

**Program model.** CF Peer Connect, a one-to-one peer support program, was first implemented as a 6-month pilot between July and December 2016. The objective was to meet the needs of adults with CF seeking to connect with their peers to share about managing daily life with a chronic illness. Twelve CF care centers participated in the pilot program by nominating patients to be peer mentors and by sharing the resource with potential mentees. After a pilot evaluation in January 2017 indicated the virtual peer support

**Table 1.** Criteria for Being a Peer Mentor.

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- Having CF or being the parent or partner to someone with CF
  - Current attendance at an accredited CF care center in the United States (if a person with CF)
  - $\geq 18$  years of age
  - Willingness to share experiences
  - Open communication style demonstrated by sharing personal story and listening effectively during phone interview
- 

Abbreviation: CF, cystic fibrosis.

mechanism was feasible and acceptable to participants (20), the program was launched nationally in June 2017 and in response to community member requests, was expanded to include parents and spouses/partners of those with CF in May 2018.

A semistructured peer mentoring model was used as the form of peer support, based on learnings from Imerman's Angels, a peer support program for people in the cancer community (J. Long, personal communication, February 17, 2016). The mentor role was intended as a person to share lived experiences, listen, and give encouragement. The mentor was not trained to provide coaching, skill building, or counseling. Peer support was the general concept, but we employed the mentoring relationship as our model and thus describe the dyad as "mentor" and "mentee."

### *Mentor Selection Criteria*

During the pilot phase, mentors were identified and nominated by a member of their CF care team; however, in subsequent phases potential mentors could elect to apply on their own. The program staff at the Foundation administered all aspects of mentor onboarding after sign-up; all had a background either in nursing or social work. Criteria for being a peer mentor are described in Table 1 and were assessed through an online application, 30-minute phone interview, email communications, and ability to complete the mentor training. Virtually all mentors who applied were accepted in acknowledgment that a variety of styles and personalities would be needed to match a range of mentee preferences. However, the structured assessment by our professional staff screened for overt displays of anger or extreme negativity or inflexibility during the interview; these were disqualifications.

### *Mentor Training*

Volunteer mentors completed a 1-hour online training created by the Cystic Fibrosis Foundation specifically for CF Peer Connect. The training included content on the scope of the mentor role, dos and do nots in peer mentoring, best practices for active listening and empathy, and how to make appropriate referrals if mentees need additional support. Role-play video segments were used to demonstrate concepts covered. Mentor candidates had to complete the online

training and pass all quizzes before joining the mentor pool. To enhance engagement with the program, mentors were also given access to a manual and a bimonthly e-newsletter to provide program news and training updates. Mentors were accepted on a rolling basis to meet mentee needs and to provide a balanced mentor pool based on age, gender, and CF experiences. Mentors were matched with up to 2 mentees at a time and could opt out of matches, go on “hold” status, or leave the program at any time.

### Matching Process

The registration and matching processes were managed by the program administrative team (2 full-time staff equivalents). Individuals requested mentorship through an online application that collected basic information. A staff member conducted an intake phone call with every individual seeking mentorship to learn about their request, set expectations about the scope of the mentoring relationship, and screen for unmet mental health needs that might place an inappropriate burden on the mentor. Mentees who indicated unmanaged mental health challenges during the screening process were referred to their care center and could be matched once they reported being connected to professional mental health support. The mentoring connection could be complementary to, but not replace, professional counseling services.

Program staff made all matches and selected the mentor based on primary criteria (topic, gender, age) as well as secondary factors (work status, relationship status, health status). Topics for matching included common life transitions as well as CF-specific issues: going to college, dating/relationships, making work/career decisions, starting a family, parenting, adult/late diagnosis, considering lung transplant, and living with a gastrostomy tube. In June 2018, as the program expanded its scope, topics for family members were added: caregiver balance, managing hospitalizations, and coping with a new CF diagnosis. Over time, specific mentorship requests led to the addition of CF-related diabetes, LGBTQ issues, post-transplant, advanced lung disease, bereavement, aging, and “adulthood.”

The match was intended to be short term (3 months) and entirely virtual—via video, phone, email, or text. The matched pair decided on a mutually agreeable communication mode and schedule. Participants were encouraged to connect weekly but could talk less or more often as desired. The frequency and total number of interactions between mentor and mentee were not tracked in this evaluation to minimize barriers to program use. Discussions were not structured nor monitored, and participants did not have to adhere to the “matching topic” in their conversations. Mentees could be rematched for any reason if requested.

Evaluation and impact data were obtained through post-match anonymous surveys using SurveyMonkey (SVMK, Inc). Surveys were sent annually in 2017, 2018, and 2019 to all mentors who had been active in the previous year. Initially, annual surveys were sent to mentees, regardless

of when during the year they had been matched. Beginning January 2018, surveys were sent to each mentee 90 days after the match started. This standardized the timing of survey receipt in relation to each mentee’s match. Key measures for evaluation included needs met, likeliness to recommend the program, and perceived benefits. The list of benefits included components of practical, social, and emotional support. Respondents were also given the option to select “I don’t feel I gained anything.” An open field for comments was provided (see online supplement for survey).

### Results

Between August 2016 and August 2019, 411 mentoring matches were made for people with CF ( $n = 333$ ) and their family members ( $n = 78$ ). Overall, 18% of matches were for family member mentees and 82% were people with CF; since May 2018 when family members were eligible to join, they now make up 40% of mentees. Mentees ranged in age from 16 to 66 years (median = 28; 74% female).

A total of 291 people with CF, parents, and spouses volunteered to be peer mentors and 228 completed the training. Mentor age range was 19 to 80 years (median = 37; 66% female). The number of matches per mentor ranged from 0 to 11. For the 411 matches, 200 mentors were used. More individuals want to be mentors than can be utilized in the program: 28 of the trained mentors never got matched and an additional 150 completed an interest form and are waiting to be brought into the mentor pool. Despite efforts to maintain a diverse mentor pool with a balance of mentors from all backgrounds, ages, and experiences, mentor profiles did not always fit the specific requests of mentees. This was especially true for male mentors because fewer males than females requested support.

The survey response rate among mentees was 28% ( $N = 93$ ). A majority (73%) of mentees reported their needs were mostly or completely met by the connection and their likeliness to recommend the program was rated 8.4/10. The most frequently cited benefits are listed in Figure 1 and include practical and general benefits of sharing lived experiences as well as social and emotional benefits. Although not specifically designed as a mental health intervention, it is also notable that a quarter of mentees reported feeling less anxious. Two-thirds of respondents reported 4 or more benefits while only 7% felt they did not gain anything. Respondents were also provided open fields for comments and a sample of positive responses are highlighted in Table 2. Negative feedback about the mentoring connection fell into 5 primary categories: not enough communication ( $n = 11$ ), match wasn’t a good fit ( $n = 8$ ), mentor needs more training ( $n = 4$ ), mentor was too stressed ( $n = 3$ ), or other administrative reasons ( $n = 3$ ).

Survey response rate among mentors was higher than mentees at 56% ( $N = 127$ ). Mentors who completed the survey and had at least one match reported several benefits to mentoring their peers, listed in Figure 2. At least 4 benefits

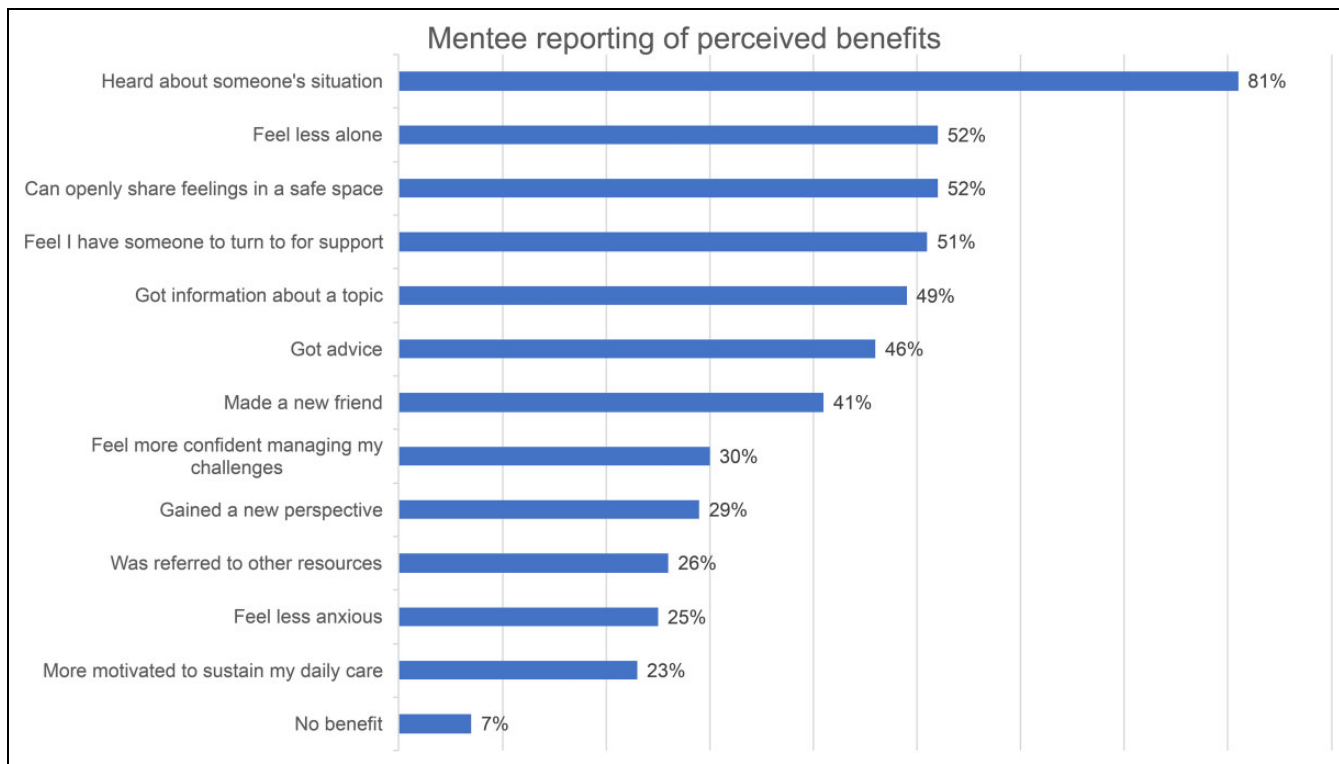


Figure 1. Mentee benefits.

Table 2. Selected Verbatim Responses to Open-Ended Questions.

What do you feel you gained from this mentoring connection?

“It was AMAZING how many parallels there were between my CF story and my mentor’s. She was the first person with CF I was able to talk with and it was incredibly cathartic.”

“I like how it’s really up to us how often we connect and what we talk about. It makes it feel really organic and natural.”

“My peer [mentor] showed empathy, was informative, and a good listener. I hope to remain friends with her in the future.”

“I enjoyed talking with someone else with CF. I learned of a new technique for the vest and overall felt motivated to do my therapy. I also enjoyed learning about someone else’s parenting experiences and challenges with CF.”

“I don’t feel alone anymore. All of my life I haven’t had another CF person to talk to and share experience with. I really found this a great benefit.”

“Having CF Peer Connect has helped even more with [isolation]. Even though having a partner helps, I know she can’t understand everything I go through like someone with CF can.”

“I like CF Peer Connect because you can talk to someone who can truly relate to you and you don’t have to explain what everything medical-related means.”

What do you feel you gained from being a peer mentor?

“I was able to be the person ‘taking care of’ another, when so often in life it had been me being taken care of. Also reminded [me] that it can be worse, and everyone has things to be thankful for. Made me realize that I like educating about CF and have a lot of knowledge about CF to offer.”

“I initially thought that becoming a mentor would give me a chance to give back to the community through my experiences . . . that I would be able to help others through tough decisions or who just had questions about different stages in life. While I hope I have been able to do that, I know for certain that the folks I have mentored also mentored me and taught me a greater sense of compassion and determination and brought be a greater sense of happiness.”

“Peer Connect makes me feel like I’m helping . . . having CF and living through the issues it presents in my life are in some way worthwhile because I have helped another through my experiences.”

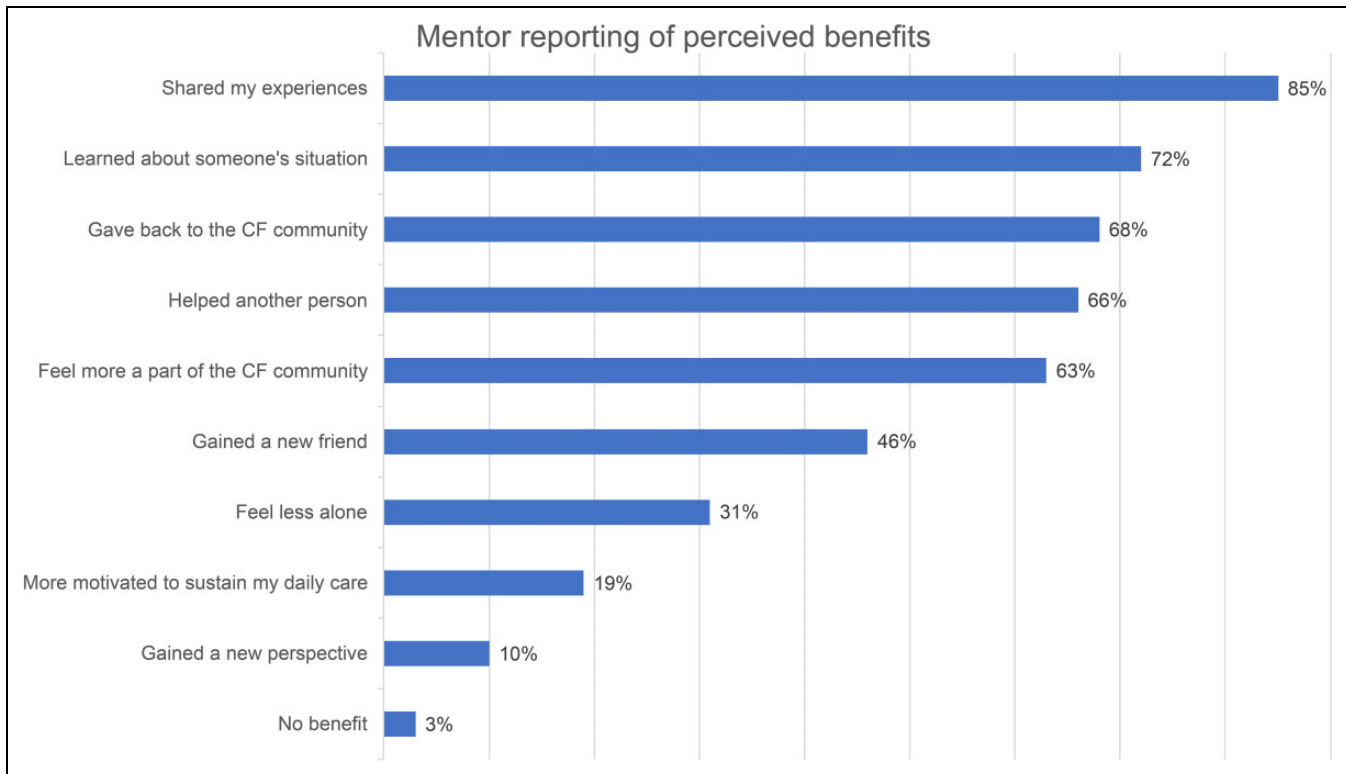
“The CFer I mentored is deceased and his mother called to thank me for him passing with a positive attitude. I feel I made a positive influence to the remainder of his life.”

“Being a mentor has been a wonderful experience. You do not always connect with all the mentees long term but occasionally you do, and the relationship of support and guidance eventually ends up being a two-way street.”

“I’ve loved connecting one on one with my mentees! It feels so good to make a new friend and do a little good for someone else.”

“My role as a mentor has met my needs and exceeded my expectations by allowing me to connect with others, to learn from them and to provide guidance and support when they need it or just being someone they can talk to who understands. I did not have anything like this in the CF community growing up and being able to provide it to someone is really amazing.”

Abbreviation: CF, cystic fibrosis.



**Figure 2.** Mentor benefits.

were reported by 60% of mentors while only 3% reported no benefits.

## Discussion

Peer support interventions can range in format and structure, as well as in the extent to which mentors are trained. Various models for peer support include groups or one-to-one format, professional- or peer-led, and in-person or virtual (8). To address needs and barriers specific to CF, the CF Peer Connect program followed a one-to-one model of support that is entirely virtual, flexible in content, and utilizes volunteer mentors with extensive life experiences to share. Some have argued for an organizational culture that endorses peer mentors as part of the management of chronic conditions (7,12) and our program benefitted from institutional backing. Data from this analysis demonstrate that this model of virtual peer support is feasible and has perceived benefits for both mentors and mentees.

Multiple types of benefits were indicated by program participants. Benefits such as receiving advice from someone who faced a similar challenge, improved knowledge, and getting referred are more practical benefits. However, the most reported benefits were social and emotional: feeling more supported, feeling less alone, and making a friend. It is possible that the unstructured, flexible nature of the mentoring relationship allowed a wide range of benefits, as the conversations could follow the interests and needs of the

individual mentees. Comments reflected the importance of talking specifically to someone with CF who understands.

Phone-based peer support is not a new concept to reduce isolation and has shown positive results in other disease communities (6). Due to the potential for cross infection of dangerous bacteria, infection protection and control measures for people with CF necessitate phone or web-based communication. Virtual peer support has not been previously evaluated in this population but can offer a degree of privacy (5), the convenience of nonsynchronous exchanges, and can provide support that is not easily found in one's own local area (14). Parents of disabled children explained that connecting virtually with others about similar challenges and feelings helped create a sense of community even without being with in the same physical space (17). Our data indicate that among both individuals with CF and their family members, virtual one-to-one peer support is acceptable and beneficial for both the mentor and the mentee and their comments reflected the importance of connection.

Recruitment of qualified mentors was not a challenge. In fact, our experience demonstrated that mentor interest exceeded demand and even with minimal training mentors were able to support mentees in ways that provided perceived benefit. High mentor interest is not surprising in the CF community given that the individuals have lived with the disease all their life and thus have vast experience to share with others. It is possible that the flexible structure of the program and 1-hour self-paced training made it possible for

mentors to commit to the role even while managing a burdensome disease and thus contributed to the high interest. Perceived benefits to mentors were also high. Data indicate that providing support was beneficial in a number of ways, which is consistent with findings that volunteering is associated with a sense of having helped someone and improved personal growth (17) and can have positive outcomes on self-esteem, confidence, life satisfaction, well-being, and depression (21,22).

Only 7% of mentees and 3% of mentors reported no benefit from the mentoring connection, indicating a negative or neutral experience for a small minority of participants. Open-ended comments indicated that communication problems were the most common complaint, followed by poor fit with the mentor. Comments about mentor skills and stress level, while few, suggest areas for further improvement to ensure optimal mentor training and support. More women than men requested mentorship; determining the barriers for men seeking support could help identify ways to increase program utilization among men.

### Limitations

In this evaluation, the frequency of connections was not tracked so the relationship between number of interactions with a mentor and perceived benefits is unknown. Additionally, data were not analyzed for differences in benefits for family members versus people with CF. Benefits were self-reported after the 3-month mentoring period and were not compared to any preintervention measures or a control group. Thus, benefits reported here can be considered subjective and correlational only. Future studies are needed to assess the impact of peer support, the nature of the mentor–mentee relationships, what factors contribute to a positive and impactful connection, as well as any negative experiences.

The ability to make personalized matches aligned on multiple factors requires a broad mentor base which was possible in this centrally managed national program. Implementation in a specific hospital setting or a geographic area with fewer patients would limit the mentor pool diversity. Conversely, expansion into international populations could broaden the diversity of experiences but would introduce language barriers and additional time zone challenges. Although the program is entirely virtual, participants need to find mutually convenient times for communicating.

This evaluation of the CF Peer Connect service allowed exploration into the range of benefits of peer support for people with CF and their family members. To strengthen the evidence for the effect of peer support on psychosocial outcomes and overall wellness, prospective research is needed to assess the impact of program benefits.

### Conclusion

Through this program evaluation, we have demonstrated that a national, one-to-one, virtual peer support program is

broadly feasible. Overall, high satisfaction and multiple, wide-ranging benefits were experienced by most mentors and mentees in the CF Peer Connect Program. Participant requests led to an expanded understanding of how the program could meet peer support needs, thus it grew beyond its original concept to reach a broader audience and address a wider range of topics. Talking to someone who understands life with CF for one-to-one virtual peer connection is a low-risk form of support for people with CF and family members who are facing challenges while managing life with CF.

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### Authors' Note

As a program evaluation, Institutional Review Board oversight and Informed Consent were not required. Program Evaluations are designed to improve program effectiveness and inform decisions about future program development. As outlined by the CDC, we (1) engaged stakeholders; (2) described the program; (3) focused the evaluation design; (4) gathered credible evidence; and (5) drew conclusions and submitted this manuscript to share findings and lessons learned (<https://www.cdc.gov/eval/guide/cdcvalmanual.pdf>).

### Declaration of Conflicting Interests

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### Supplemental Material

Supplemental material for this article is available online.

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