



2024-2025 Impact Report:

Financial Hardship Assistance Program

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Program Background

Unmet Needs in the CF Community

Financial hardship is widespread throughout the cystic fibrosis (CF) community, not only impacting quality of life, but overall health outcomes. Nearly 70 percent of people living with CF in the United States face financial challenges related to medical bills, however, the financial burden of CF extends well beyond healthcare costs. One in four people living with CF experience food insecurity, 10 percent experience housing insecurity, and almost 10 percent lack reliable transportation. Sixty percent of the CF population are now adults, and the financial hurdles associated with adulthood are becoming more consequential for the overall well-being of the CF community. Financial stress can lead to poorer health outcomes by limiting access to healthy foods, a safe and clean environment, and reliable transportation, all of which have a direct impact on health. Fear of stigma can hold people back from seeking the financial help that they need. This is where BEF's Financial Hardship Assistance Program steps in.

In 2017, BEF launched its Disaster Relief Program in response to Hurricane Harvey, which provided assistance to over 50 CF families in need in the Gulf Coast area in Texas and Mississippi. Later, BEF expanded disaster relief efforts to families affected by wildfires in California and other natural disasters. In early 2020, BEF relaunched its disaster relief efforts with the COVID-19 Cystic Fibrosis Disaster Relief Patient Assistance program.

BEF awarded over \$275,000 in relief from winter 2020 to summer 2022.

The Disaster Relief and COVID-19 programs were reactive, addressing the immediate needs of families during natural disasters and the prolonged pandemic. After thoughtful program evaluation and a generous donation from the Caruso Family Foundation, BEF established a more proactive program that addresses financial need due to unforeseen issues that may not be related to CF. The resulting program, informed by contributions from the broader CF community, followed best practices learned from previous programs.

The Financial Hardship Assistance Program officially launched in early March 2023. The program awarded over \$240,000 to over 100 families from March to December 2023.

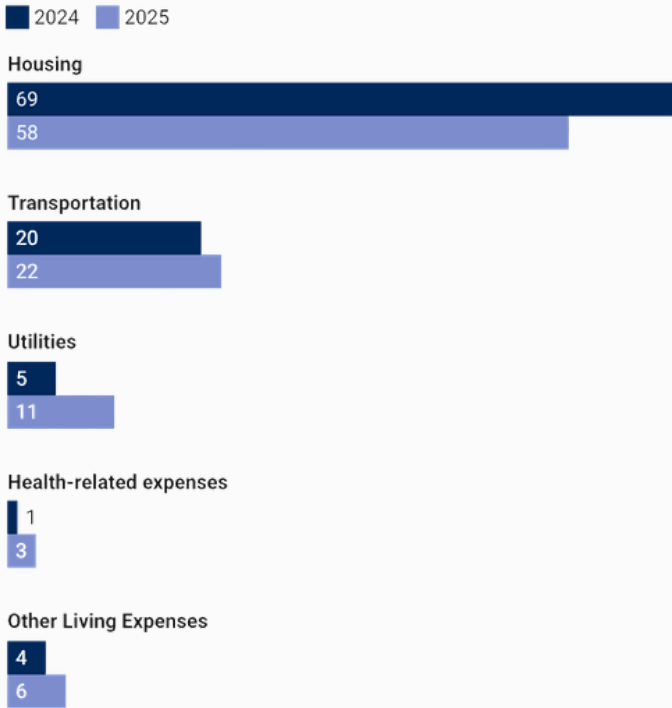
Since March 2023, the Boomer Esiason Foundation has awarded **over \$900,000** in financial hardship assistance to families living with CF from across the country.

The BEF Financial Hardship Assistance Program awarded **over \$580,000** to **over 250 families** in 2024 and 2025.

Distribution of Funds

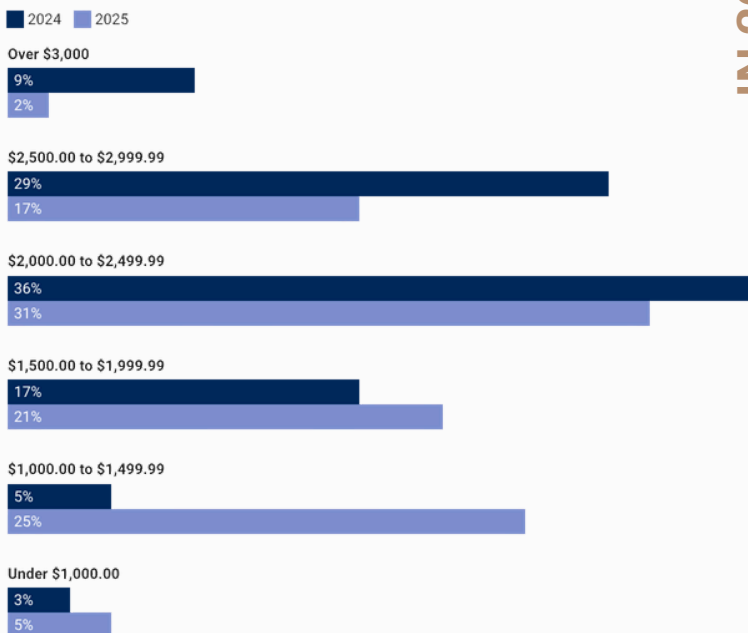
Areas of Need

Percent of Funds Allocated per Category



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Percent of Awards by Amount Range (\$USD)



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IN 2024

In 2024, **69%** of award funds went towards housing, including rent, mortgage, home repairs, hotel stays, and relocation expenses. Transportation (including car payments, insurance, and repairs) was the second largest category, making up **20%** of all funds. Health-related expenses included medical and dental expenses not covered elsewhere, and other living expenses included legal fees, immigration fees, food, funeral expenses, child needs, and loans.

\$2,212

average award in 2024

IN 2025

In 2025, housing accounted for **58%** of award funds, including rent, mortgage, moving, travel and hotel expenses, and home insurance. Transportation, including car payments, car repairs, and car insurance, accounted for **22%** of award funds. Other living expenses included legal fees, loans, taxes, credit card payments, and living expenses.

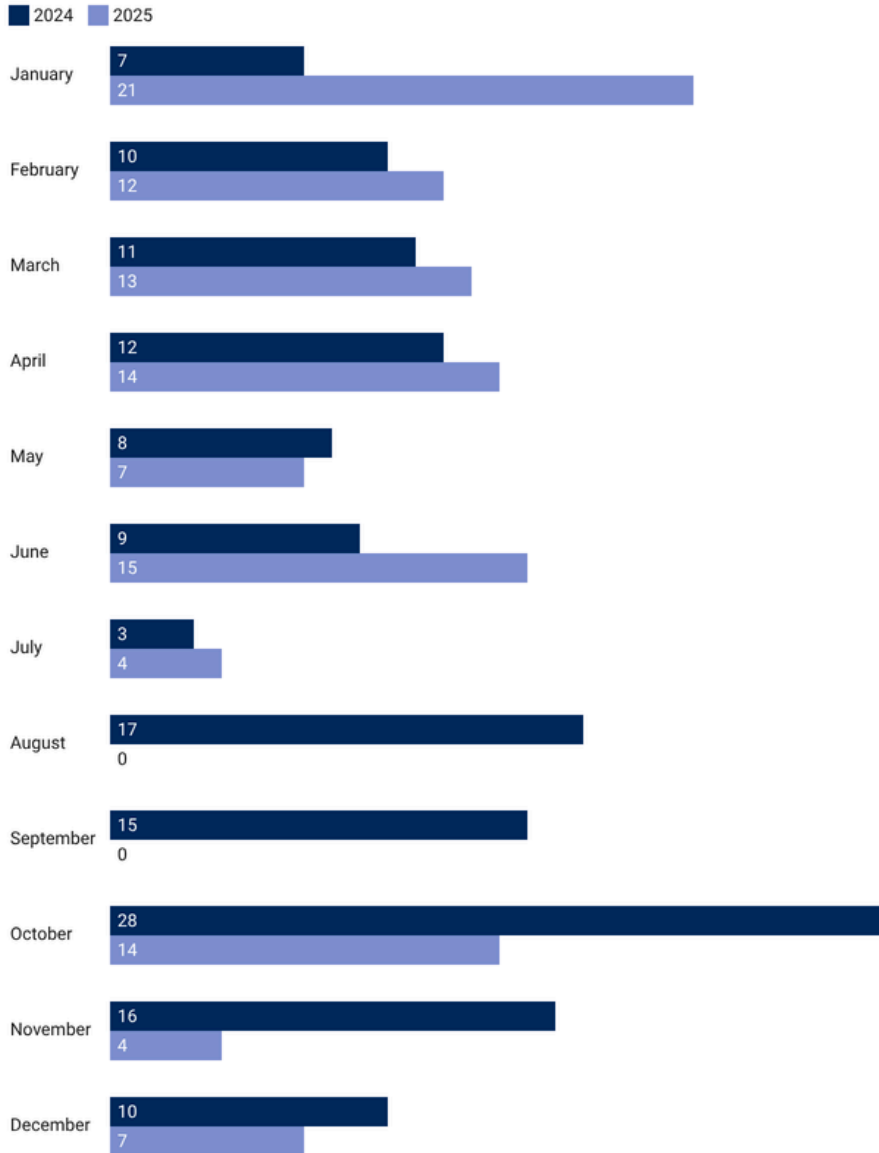
\$1,853

average award in 2025

Distribution of Funds

Since the program's launch, it quickly gained traction through national outreach to CF social workers. In the program's first year, BEF observed that many requests aligned with the initial \$3,000 target. Over time, however, BEF found that awards in the \$1,000-\$1,500 range met typical needs while supporting the equitable and efficient distribution of BEF's funds. After a brief pause in the program from August through September of 2025, BEF refined its approach, adjusting both the number and size of awards to better reflect observed need and to ensure the program's long-term sustainability.

Number of Awards per Month



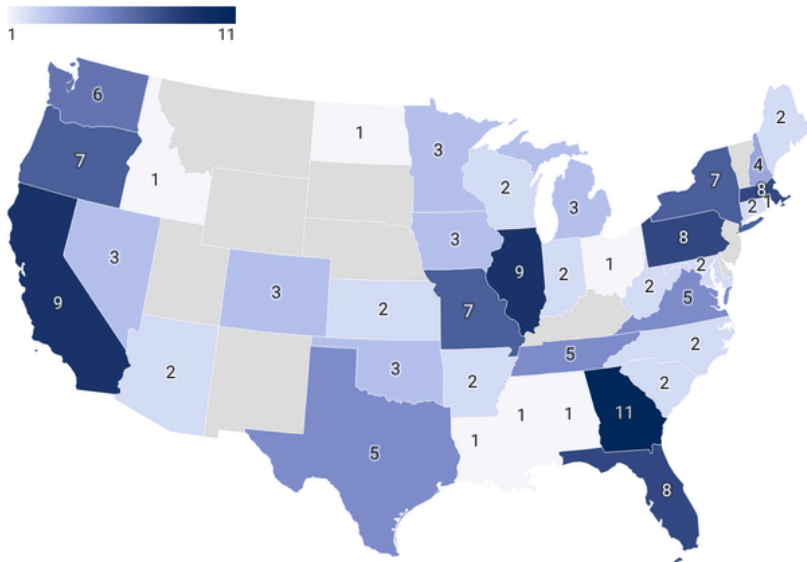
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October had the most awards of any month in 2024 with 28 awards, more than double the monthly average (12). This was most likely due to natural disasters in the South and targeted outreach efforts to care centers in Georgia, as well as North Carolina and Tennessee. **1 in 4** awards made in October 2024 were made to patients and families from Georgia, which was also the state with the highest number of awardees in 2024.

Distribution of Funds

From 2024 to 2025, BEF distributed awards to families from 42 states across the country.

Number of Awardees per State (2024)

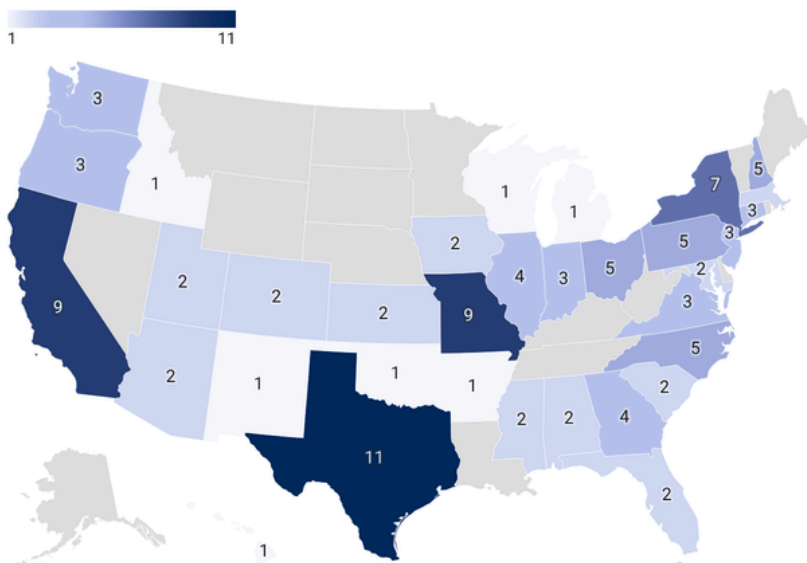


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In 2024, **Georgia** was the state with the most awardees (11), followed by **California** (9), **Illinois** (9), **Florida** (8), **Pennsylvania** (8), and **Massachusetts** (8). This differs from the distribution of the CF population throughout the country, as Georgia has a population of less than 1,000 people living with CF, compared to California, which has a population of over 2,500 people living with CF. This is most likely due to BEF’s outreach to centers in Georgia following natural disasters.

In 2024, **50%** of awardees lived in urban areas (area home to 200,000 people or more) and **50%** lived in rural areas. According to the 2020 Census, about **20%** of Americans lived in rural areas.

Number of Awardees per State (2025)



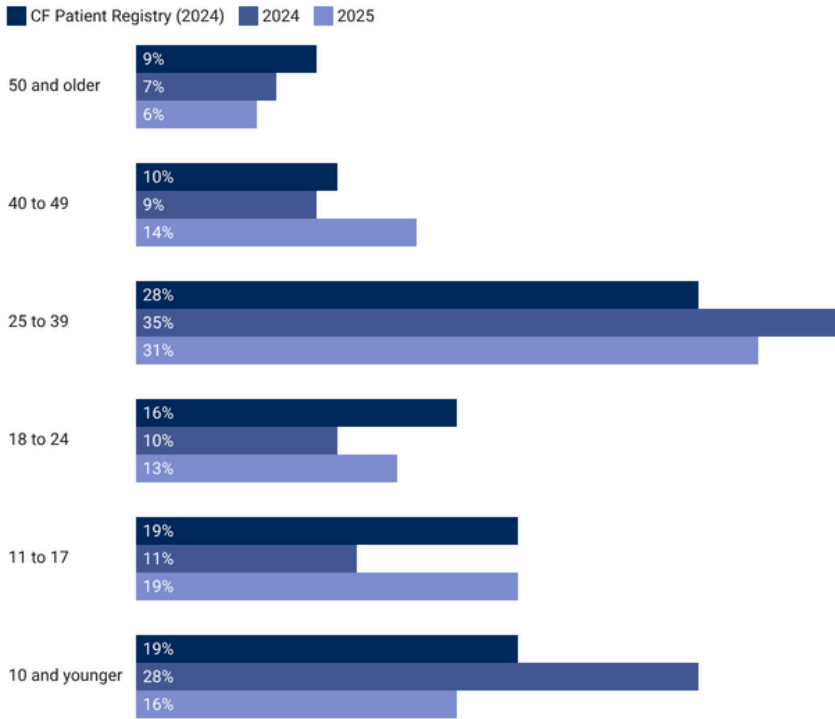
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In 2025, **26%** of awards came from three states- **Texas** (11), **California** (9), and **Missouri** (9). The **29** families referred from these states came from **21** different centers, highlighting BEF’s wide reach in those states.

In 2025, **60%** of awardees lived in urban areas and **40%** lived in rural areas.

Awardee Profiles

Age Range of Person Living with CF



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There were more families with children younger than 10 years of age awarded in 2024 compared to 2025. The age ranges from 2024 more closely resemble the ranges from 2023, when over **30%** of people living with CF in the household were **younger than 9**.

The age ranges for people living with CF in the household in 2025 more closely resembled age ranges of the 2024 CF Patient Registry.

Upcoming changes to federal and state programs may affect individuals and families living with CF who are enrolled in Medicaid and SNAP. 10.9 million people may lose Medicaid coverage and SNAP enrollment may decrease by 4.7 million people because of recent policy changes. BEF may see an increase in applications in 2027 if individuals and families experience disruptions and have difficulty enrolling in these programs, and experience related financial stress. Families may also experience financial stress related to increasing energy prices and potential inflation as of April 2026. As colder temperatures return, families may experience higher utility bills, which may drive requests for assistance with utilities.

2024

71%

of awardees were enrolled in a government assistance program

54%

of awardees were enrolled in Medicaid

37%

of awardees received SNAP benefits

2025

72%

of awardees were enrolled in a government assistance program

50%

of awardees were enrolled in Medicaid

31%

of awardees received SNAP benefits

Survey Data

BEF distributed an online survey to **257** past awardees via email. **119** responses were recorded (one response per household).

43%

response rate for 2024 survey

50%

response rate for 2025 survey

50%

of all respondents were adults living with CF

50%

of all respondents were parents, partners/spouses, or care providers of people living with CF

\$30,000 - \$39,000

median household income

3

median household size

The median income of survey respondents was **\$30,000 to \$39,999**, less than half of the US median income, \$83,730. **49%** of survey respondents worked full or part time.

Of respondents living with CF, **31%** identified as “Unable to work due to disability,” while **25%** identified as “Employed full-time.” According to the 2024 CF Patient Registry, about **17%** of adults living with CF are disabled and **48%** are employed full-time. **More than half of respondents who identified as “unable to work due to disability” reported incomes of less than \$30,000.** This indicates that people living with CF who are unable to work due to disability and live on low incomes may lack the resources available to withstand unexpected financial hardships. People living with CF who have worse health outcomes are reasonably less likely to work due to their health, and are more vulnerable to financial insecurity. This underscores the urgency to continue to develop novel treatments and improve care to ensure the highest quality of life for all those living with CF.

Survey Data

About **71%** of survey respondents reported taking an approved CFTR modulator. According to the [2024 CF Patient Registry](#), **92.3%** of the total CF population is eligible for CFTR modulators by genotype, and **89.6%** of those eligible individuals take an approved modulator.

Healthcare costs are a serious financial strain for all Americans, not only for those living with CF. A [study](#) from March 2026 found that **55%** of households earning less than \$24,000 annually reported making at least one trade-off in daily living expenses in order to afford their healthcare, including skipping meals, driving less, and cutting back on utilities. The same study also noted that Americans who report being in “poor” or “fair” health are more likely to report making these tradeoffs to pay for healthcare. From BEF’s survey, **67%** of respondents reported their health as “poor” or “fair” and over **40%** of respondents reported an annual income of less than \$30,000. People living with CF are likely making similar tradeoffs between daily living expenses and healthcare, which may be at an even greater rate due to people living with CF’s high healthcare utilization.

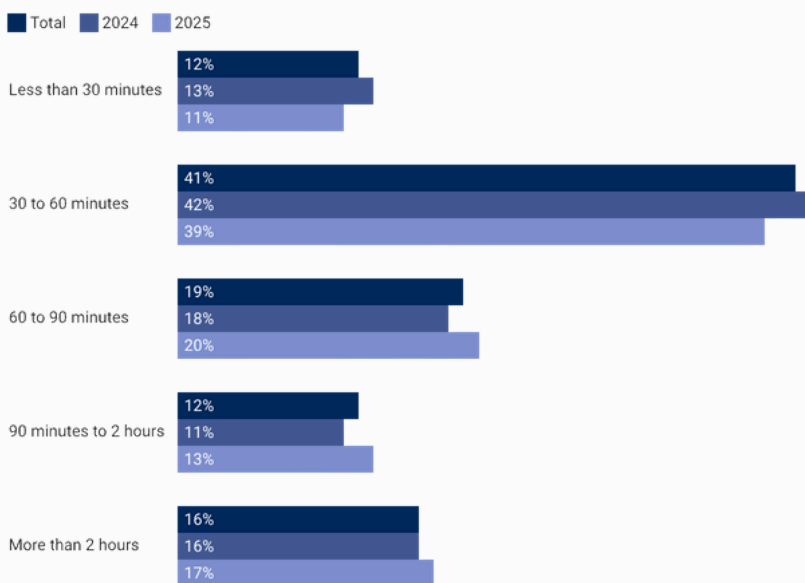
76% of respondents strongly agreed or agreed that CF impacted their ability to pay household bills and **96% of respondents were unable to accumulate any savings in the past year.** In a [survey](#) by the Cystic Fibrosis Foundation, **54%** of people living with CF reported being unable to accumulate savings in the last year because of the burden of medical costs. While BEF’s survey did not ask for a reason why individuals were unable to accumulate savings, survey results demonstrate that across income, employment, and health status, families living with CF struggle to pay household bills and to accumulate savings.

66%

of respondents ranked rent and mortgage payments as the area that causes them the most financial stress, which roughly reflects the distribution of program funds.

- 1st Rent/mortgage payments
- 2nd Groceries
- 3rd Utilities

Percent (%) of Respondents' Length of Commute to CF Center



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Access to CF Center

Most respondents lived less than one hour from their care center. **79%** of respondents accessed their care center by car. Those who did not have a car accessed care by a ride from a friend or family member (5%) public transportation (5%), or a ride-share service (4%). Other transportation (6%) included medical transportation, Rideline through Medicaid, a ride with AAA, or a combination of the offered options.

Interview Data

Causes of Financial Hardship

Living with cystic fibrosis and managing CF care can create barriers for individuals and families to develop safety nets for hard times. As mentioned, BEF's survey of awardees found that **96%** of individuals and families living with CF have not accumulated any savings in the past year. When people living with CF and their families experience disruptions to their incomes, from missed work due to hospital stays, losing a job because of caregiving responsibilities, delays in disability assistance, or an organ transplant, they often lack the additional resources to make ends meet. The financial, physical, and emotional burden of CF care can create an unstable financial position for individuals and families managing the disease, which can be further destabilized when encountering life challenges unrelated to CF, such as housing transitions, job loss, and relationship changes.

While living with CF comes with its own specific set of pressures and difficulties, CF caregivers described a distinct pressure to provide for their household, to give care, and to maintain a presence of strength and calm for their loved ones, all of which felt overwhelming. Several interviewees used the phrase "breakdown" to describe the pressure felt during times of financial and health stress. One interviewee "felt like I had no control" when their child was sick, and felt frustrated because "I don't know how to help [my child]. I don't know what [they're] experiencing. I wish I could take it away." This lack of control over finances, health, and stability takes an immense mental and emotional toll on caregivers.

"It's hard, with a CF patient or a CF child, to get a full-time position... You know they count on you to be there for your job. They're not as flexible or understanding... I ended up having to resign from the current job that I had because I had missed so many days, and I had used up all of my [paid time off], and so that was devastating."

Several households experienced hardship when they transitioned from a dual-income to a single-income family, either due to job loss, extended medical leave, or a change in relationship status. This was experienced by both couples and families with children. Complications of CF can lead to disruptions in income, as several households reported one household member having to leave their job due to a CF-related hospitalization or medical emergency, either to receive care themselves or to take care of a child or spouse. Medical emergencies disrupt income and often are accompanied by an influx of costly medical bills, which compound financial strain. Interviewees' stories highlight a major barrier to developing a safety net: choosing between receiving medical care or earning income.

"I was trying to be strong for my husband, but I would go into the hallway and just, like, break down."

Several parents of children living with CF noted that they could not rely on traditional daycare centers for childcare because of the risk of their child catching an infection. One single parent described choosing a flexible job over a higher-paying job so that they could keep their child out of daycare. The lack of safe childcare for children living with CF is extremely challenging for parents of children living with CF, especially single parents, again posing the impossible choice between health and financial stability.

"... it all happened at a horrible time ... [My husband] was hospitalized, he wasn't at work, obviously, he couldn't work, and we were surviving on only my income."

Interview Data

Effects of the Program

People living with CF and their family members described feeling an intense pressure when their finances were strained, and the BEF Financial Hardship Assistance Program helped to relieve some of this pressure. Interviewees described feeling “a sense of relief,” “a part of the weight is taken off my shoulders,” “a huge relief,” and “able to take a breath of fresh air” after receiving assistance from the program.

“[The assistance] definitely reduced my stress, and it made me feel really supported, like, I wasn't just having to figure this out on my own. Instead of feeling very anxious and overwhelmed, I was able to put that aside because I knew that it was being taken care of.”

Interviewees noted that assistance from the program allowed them to stay in their current residence, pay basic utility bills, buy healthier groceries, and focus on healing. Testimonies from interviewees revealed that the Financial Hardship Assistance Program met one of its major goals: to provide stability in times of crisis for families living with cystic fibrosis. In addition to material support, the BEF Financial Hardship Assistance Program also provided mental and emotional support for awardees. Some interviewees expressed that knowing that the program exists and that there are resources available to the CF community was comforting in a time of distress.

“When I first found out she had CF and we were going through those things, it was so defeating, but to have somebody hold your hand, whether it was financially, emotionally, what have you, it meant everything to us.”

In addition to expressing gratitude for BEF, participants also thanked their CF clinic social workers and CFF Compass for informing them about the program and guiding them through the application process. Some recipients heard about the program from their CF social workers and others told their social workers about the program to help more families. One interviewee noted that the program’s assistance started a conversation with their children about helping others:

“The [children] didn't realize that these kinds of things existed, so that opened up a conversation about how people donate to help others and keep foundations like this alive and going strong to help other families throughout the country and the world... They learned about how when they get older, they can help foundations and help other families, because they were helped as well. So you feel that impact and know how important it is.”

The Financial Hardship Assistance Program not only provided short-term relief to families in hard times, it established a sense of trust and support within the CF community, letting families know that there was a foundation that had their back when they needed help. Interviewees noted that part of the relief that they felt was from knowing that BEF and the Assistance Program existed to provide relief when it matters most.

Interview Data

Social Worker and Case Manager Insights

Of the **38** survey respondents that answered, “How did you find BEF’s Financial Hardship Assistance Program?” **19** found the program directly through their social worker. Other recipients found the program through CF Compass or directly through BEF.

BEF reached out to several social workers to better understand the program’s reach, strengths, and weaknesses, as well as community needs. Social workers praised the program, noting that BEF was able to quickly and effectively address their patients’ most urgent needs. Social workers’ commended the program’s flexibility, accessibility, and responsiveness. They noted that while there are many assistance programs available to the CF community, there are few that offer direct assistance for living expenses, and appreciated that BEF’s program filled that gap. To improve the application, social workers suggested that some requirements, including the letter stating an applicant’s needs, could be clarified on the application information page.

Social workers’ assessments of their community’s needs reflected findings from awardee interviews, as housing, transportation, and utilities were noted as the areas of greatest need. Food insecurity was identified as a pressing issue in the CF community, considering the elevated nutritional needs of the CF community and the increasing cost of groceries. Local resources like food pantries were described as inadequately stocked and difficult to access for patients in rural areas.

As previously discussed, healthcare costs are rising and insurance is increasingly difficult to navigate. Social workers noted these developments and added that many of their patients either recently lost health insurance or struggled to afford CF care because of challenges accessing assistance. One social worker pointed out that copay assistance was becoming less effective at decreasing patients’ out-of-pocket costs because of copay accumulator and maximizer programs in insurance plans, which divert assistance from going toward patients’ deductibles. Another social worker noted that decreases in assistance for supplements also strained patients living with CF, especially those whose medical nutrition was not covered by Medicaid, and used SNAP benefits to cover their medical and everyday nutritional needs.

BEF also spoke with managers of the Cystic Fibrosis Foundation’s Compass program, which provides free, one-on-one support and CF-specific resources for community members. Compass managers refer patients and families to BEF’s program for assistance with health-related social needs because BEF is a reputable organization that responds quickly and the program application is accessible. Compass managers noted that there is a lack of assistance for car repairs, which are essential to ensure that patients can reach their care centers for treatments, and BEF’s program fills this gap in the community. Like social workers, Compass managers noted that insurance and out-of-pocket costs are a strain on individuals and families living with CF. BEF’s program met the needs of patients and families facing a once-in-a-lifetime emergency, because the program provides assistance once to one family. While this aspect of the program provides relief to families in distress, Compass managers noted that this stipulation may cause people to delay seeking help due to fear of a potential future event that may be worse. While one-time assistance may be transformative for some, it can be a “band-aid” over underlying health-related social issues.

Program Impact

Strengths

Responses to the program were overwhelmingly positive, as award recipients and social workers appreciated the easy application process and quick response times. Survey respondents also noted that the assistance was effective and met their needs, while interviewees praised the flexibility and responsiveness of BEF staff. The Financial Hardship Assistance Program provided financial relief for individuals and families in areas where they felt the most pressure, and provided meaningful stability during emergencies.

Social workers also noted that BEF's program was one of the few assistance programs available to people and families living with CF that could help with living expenses. There are several assistance programs available for medications, copays, and other medical expenses, but few available that cover what social workers identified as their patients' greatest needs: rent, transportation, and food. BEF fills an important gap in the CF community, relieving pressure for individuals and families during periods of uncertainty.

"Now that I'm cleared to go back to work, I can pay my own bills now... [the Financial Hardship Assistance] was just to help get me back on my feet."

Suggestions for Improvement

Survey respondents and interviewees both requested the ability to apply more than once to the program. Others noted that at times it was difficult to gather all of the documents necessary for the program application. In interviews, awardees noted that there was some confusion about what expenses they could request assistance for, and a social worker noted that the requirements for a letter of support were different on the website and on the application. BEF evaluates applications on a case-by-case basis and is limited in certain areas for individuals receiving government assistance, which is unclear until the application is received.

Next Steps

BEF can continue the success of the Financial Hardship Assistance Program by providing financial assistance to individuals and families living with CF during periods of uncertainty and distress. Based on surveys and interviews, the application, review, and delivery processes are effective and timely, but BEF can improve the clarity of its messaging on its website and application materials. BEF can continue its outreach to social workers and CF centers across the country to increase the reach of our programs. Outside of the function of the Financial Hardship Assistance Program, BEF can continue to advocate for policies that make healthcare more affordable for the CF community, continue the development of effective treatments for all people living with CF, and amplify the voices of the CF community.

Program Impact

Key Findings

Many families and individuals living with CF struggle to manage everyday financial pressures in addition to the financial and time burden of living with a chronic, life-limiting condition like cystic fibrosis. The vast majority of survey respondents reported being unable to accumulate savings and most respondents earned annual household incomes far below the national median, and interviewees cited the financial pressures of living with cystic fibrosis as a major driver of financial hardship.

Rent and mortgage payments were the most pressing area of financial need, which was reflected in both the distribution of funds and survey findings. Survey respondents ranked rent and mortgage payments as the area that causes them the most financial stress.

Survey data showed that many families rely on cars to access their care center and most live less than 60 minutes from their care center. Application data also revealed 50% of award recipients lived in rural areas. Access to care is closely related to transportation reliability, which was reinforced by social workers. One survey respondent noted that they had to rely solely on telehealth because they could not afford car repairs, and therefore could not physically access their clinic. According to a 2024 survey from CFF, 10% of people living with CF lack reliable transportation.

Social workers commented that insurance is becoming more expensive and is covering less for CF families. One social worker specifically cited copay accumulator and maximizer programs as a source of financial stress for families who find their copay assistance inadequate to cover their high-cost medications.

The mental and emotional toll of living with CF and caring for a person living with CF can be intense, which can be further compounded by financial stress. Interviews revealed the pressure that many families feel when experiencing a life challenge, such as losing a job or being hospitalized for an extended period of time. Financial assistance helped to relieve some of these pressures and provided stability for families in times of uncertainty.

"I didn't realize just how much you guys do, I'm on the website all the time now. I'm always trying to learn about cystic fibrosis. I'm just trying to keep educated, and I always see what you guys do and you guys are really amazing. You guys honestly saved our lives, I can't thank you guys enough."

Additional Programs

Nebraska Medicine and BreatheStrong CF both received grants from the BEF Financial Hardship Assistance Fund to support local initiatives closely aligned with the goals of the Financial Hardship Assistance Program.

Nebraska Medicine

In 2024, the Pediatric CF Team of the Nebraska Regional CF Center located at Children’s Nebraska received a \$20,000 grant for a two-year project ending in April 2026 to support their efforts to address food insecurity in their community. Children’s Nebraska purchased Hy-Vee, a regional grocery chain, gift cards to distribute to families in need. In the first year of the grant from May 2024 to April 2025, Children’s Nebraska distributed 128 \$80 gift cards to their community. More than one-third of the center’s patient population received assistance– 64 families and 75 individual patients in Nebraska, Iowa, Kansas, and South Dakota.

Case Examples

- A single parent family that experienced an insurance change and has a child reliant on G-tube supplementation that no longer has formula coverage through insurance
- An adult patient who relies on disability and SNAP benefits but faced a reduction in SNAP benefits from ~\$300 a month to ~\$100
- A single parent household with an overdrafted bank account needing a bridge until additional benefits were received, including SNAP
- A severe thunderstorm caused a family to lose power for several days spoiling the food that family had

BreatheStrong CF

BreatheStrong CF received a \$7,500 grant in 2024 for their Critical Needs Initiative Program, which provides families living with CF with financial assistance for food, gas, and utilities. The grant supported 33 grants at an average of \$227.33. The program primarily assisted families in Georgia and Florida. The average household had 3.57 people, with an average household income of \$26,208.68.

45.4% of applicants sought assistance with food and groceries. 39.3% requested help with both gas/fuel and groceries, while 6% prioritized food/grocery assistance over gas/fuel. 6% requested help exclusively with gas/fuel. Requests for support were fulfilled by gift cards. 87.9% requested Wal-Mart, 6% requested Target, and 3% requested Shell Gasoline.

BreatheStrong CF also received a \$10,000 grant in 2025 for their Critical Needs Initiative Program. In 2025, BEF’s grant supported 43 instances of support between April 1 and May 2, 2025. Families that sought out the program cited job loss, reduced work hours, rising food and utility costs, delays in public assistance benefits, and increased medication expenses as reasons for financial hardship.

The entire program distributed \$72,402 (including \$10,000 from BEF) in grocery and gasoline gift card assistance to individuals and families living with cystic fibrosis. This support reached 95 unique households, with 60% requesting grocery assistance, 4% requesting fuel assistance, and 35% requesting a combination of both.

Appendix



Using the Department of Transportation's Grant Project Location Verification Tool, BEF determined if a program participant lived in an urban (population greater than 200,000 people) or rural area (population less than 200,000 people). The tool also allowed us to determine if a participant lived in an Area of Persistent Poverty or a Historically Disadvantaged Community. This tool screens for areas disproportionately affected by poverty, pollution, underdevelopment, high energy costs, and other socioeconomic burdens, which can help to illuminate the social determinants of health that families may face.

56% of 2024 program awardees and 47% of 2025 program awardees lived in an Area of Persistent Poverty and/or a Historically Disadvantaged Community. Families may face financial hardship due both to larger structural disadvantages and the burden of living with CF.

Data on gender and race were collected for 2024 awardees via survey and for 2025 awardees via the initial application.

2024 Survey Data:

Gender:

- 73% of respondents identified as female
- 25% of applicants identified as male
- 2% of applicants preferred not to say

Race/Ethnicity:

- 78% of respondents identified as White
- 11% of applicants identified as Black or African American
- 8% of applicants identified as Hispanic or Latino
- 3% of applicants identified as some other race or multiracial

2025 Application Data:

Gender:

- 79% of applicants identified as female
- 20% of applicants identified as male
- 1% of applicants preferred not to say

Race/Ethnicity:

- 72% of applicants identified as White
- 14% of applicants identified as Black or African American
- 14% of applicants identified as some other race or multiracial

Due to a programming error in both the 2024 and 2025 surveys, respondents who answered "Yes" to the questions "Are you taking an approved CFTR modulator?" skipped several questions, including "How did you find BEF's Financial Hardship Assistance Program?," "How was your experience with the application process?," "How do you think BEF's Financial Hardship Assistance Program can improve?," and the question to schedule an interview. Thus, interviews were conducted only with people who replied "No" to the question "Are you taking an approved CFTR modulator?." This was detected during the analysis of the 2025 survey responses and a follow-up message was sent to respondents who answered "Yes," and several additional interviews were conducted with these participants to better reflect the experiences of all award recipients.