

PATIENT ASSISTANCE RESOURCES



Editor's Note:

The following document reflects resources offered by external companies and organizations for people with cystic fibrosis (CF) and their loved ones. The information in this document has been provided by the companies and organizations, and while the Cystic Fibrosis Research Institute (CFRI) attempts to keep the information current, some assistance programs may have changed. If you see a resource that is missing, please reach out to cfri@cfri.org.

Special Thanks:

This resource document was created with the assistance of CFRI's Diversity and Inclusion Committee, for the purpose of making pharmaceutical, medical, financial, and recreational information and support more accessible to people with CF and their loved ones. To promote language access, the following information has been translated to Spanish and can be downloaded at [CFRI Español](#).

For additional resources, contact CFRI
Toll free 1.855.cfri.now **(1.855.237.4669)**
www.cfri.org

The development of this Patient Assistance Resource document was supported through educational grants from the following:



TABLE OF CONTENTS

<u>CFRI Community Resources</u>	<u>04</u>
<u>Pharmaceutical Assistance Programs</u>	<u>05</u>
<u>Financial Assistance</u>	<u>08</u>
<u>Scholarships</u>	<u>14</u>
<u>Physical & Recreational Activities</u>	<u>18</u>
<u>Insurance, Billing & Legal Assistance</u>	<u>20</u>
<u>Additional Resources (Search Engines, Media)</u>	<u>23</u>
<u>International Resources</u>	<u>25</u>



CFRI COMMUNITY RESOURCES

CFRI offers a variety of resources to support people with CF and their families. All activities listed below are free.

Psychological Support Programs & Classes (virtual):

- Nationwide counseling support for people with CF and their families
- Caregiver support group for parents of children with CF, & parents, spouses, and partners of adults with CF
- Support group for adults with CF
- Support group for teens with CF
- Bereavement support group
- Post-transplant support group
- Meeting for the Spanish-speaking CF community
- Mindfulness sessions for the CF community

Wellness Classes for CF patients and family members:

- Core & Strength
- Gentle Yoga
- Mat Pilates
- GROOV3

CFRI Community Retreats

- CF Summer Retreat for people with CF (18+) and their family members and friends
- Embrace: A virtual retreat for mothers of children & adults with CF

PHARMACEUTICAL ASSISTANCE PROGRAMS

AbbVie – CREON® CFCareForward

Services offered:

- Co-pay assistance for CREON (pancrelipase)
- Multivitamin coverage
- Medication refill reminders
- Educational emails
- Support hotline

Eligibility:

- Individuals with Exocrine Pancreatic Insufficiency
- Patients with commercial prescription insurance coverage for CREON (Pancrelipase)
- People with federal, state, or government-funded insurance programs cannot access co-pay assistance or multivitamin coverage

Contact: 1-855-227-3493

Genentech – Pulmozyme Co-pay Program

Services offered:

- Co-pay assistance to help cover additional out-of-pocket costs for Pulmozyme, after you pay \$30 for each 30-day supply (Maximum \$10,000/year)

Eligibility:

- Are taking Pulmozyme for an FDA-approved use
- Have commercial (private or non-governmental) insurance
- Live and receive treatment in the US or US territories

- Are not receiving assistance through the Genentech Patient Foundation or any other charitable organization for the same expense

Contact: 1-877-794-8723

Gilead – Cayston Access Program

Services offered:

- Provides assistance for those who are uninsured or who have been denied coverage for Cayston
- Those who qualify may also qualify for assistance for additional or replacement parts for their Altera Nebulizer System

Eligibility:

- Meet income requirements
- No insurance coverage, or insured but denied coverage for Cayston

Contact: 1-877-722-9786

Nestlé Health Science –Live2Thrive

Services offered:

- Co-pay assistance on eligible Nestlé Health Services pancreatic enzyme prescriptions (12 fills of a 30-day supply or 4 fills of a 90-day supply)
- Free vitamins and supplements
- Loyalty rewards where participants can earn points and redeem them for a variety of nutritional and respiratory health products



Eligibility:

- Individuals with a valid prescription for an eligible Nestlé Health Science pancreatic enzyme
- Residents of Massachusetts, Michigan, Minnesota, or Rhode Island cannot receive rewards through the Live2Thrive program
- People with federal, state, or government-funded insurance programs are not eligible for the Live2Thrive program

Contact: 1-888-936-7371

Vertex Pharmaceuticals – Guidance & Patient Support (GPS)**Services offered:**

- Co-pay Assistance Program (Maximum \$20,000/year)
- Understanding your insurance plan
- Plan medication refills
- Nutritional & physical activity guidance
- Educational resources

Eligibility:

- Individuals with a Vertex modulator therapy prescription
- Not available to individuals with government-funded insurance

Contact: 1-877-752-5933



Viatis – PODCARE+ (Tobi Podhaler)

Services offered:

- Insurance coverage reviews
- Therapy support calls as a periodic check-in
- Tobi Podhaler savings card for up to \$14,000/year

Eligibility:

- Tobi Podhaler savings card is not valid for uninsured patients or those who are enrolled in a federal or state healthcare program
- Individuals must have commercial insurance

Contact: 1-877-999-8624 / customer.service@viatis.com

Viatis –Patient Assistance Program

Services offered:

- Certain medications may be free to patients with a demonstrated financial need

Eligibility:

- Applicants must be fully uninsured, or if insured, have no prescription drug insurance
- The requested medication must be prescribed by a licensed U.S. healthcare professional for a FDA approved indication

Contact: 1-888-417-5780 ([Group 1 medicines](#)) / 1-888-417-5782 ([Group 2 medicines](#)) / customer.service@viatis.com

FINANCIAL ASSISTANCE PROGRAMS

Bonnell Foundation – Medical Assistance Program

Services offered:

- Financial assistance not covered by insurance or any other program to help cover various costs

- Examples include: Durable medical equipment, counseling services, medical care (up to \$500 twice per year), ambulatory services, and CF medications

Eligibility:

- Applicants must provide a letter confirming CF diagnosis
- Provide related bill(s) requesting direct payment

Contact: 1-248-520-2329 / info@thebonnellfoundation.org

Boomer Esiason Foundation – Patient & Family Assistance Programs

Services offered:

- Transplant grants
- IVF Grant
- Financial Hardship Assistance Fund

Eligibility:

- Applicants must be a person with CF, and a US citizen or legal permanent resident
- Must demonstrate proof of financial hardship and consequently cannot meet financial obligations
- Additional eligibility criteria vary depending on program and can be found on website

Contact: 1-516-746-0077 / info@esiason.org

Claire’s Place Foundation – Hospital Stay Grant

Services offered:

- One-time financial assistance for families who have someone with CF in the hospital
- Examples: rent, utilities, and other monthly bills
- Grants range from \$500-\$3,500/one grant recipient



The Cystic Dreams Fund – General Financial Grants

Services offered:

- Provides general financial assistance to individuals and families struggling with the costs associated with cystic fibrosis
- Assistance grants are usually issued through the form of direct payments to outstanding bills

Eligibility:

- Applicants must be the parent or legal guardian of a minor child with CF or be an adult with CF
- Verification of CF status
- Verification of bill for which you are requesting financial assistance (mortgage, rent, car payments, or fertility treatment bills are not accepted)

Contact: 1-978-290-0635 / info@cysticdreamsfund.com

Cystic Fibrosis Family Connection – Emergency Fund

Services offered:

- Financial assistance for expenses temporarily beyond a family's means, such as lodging for a transplant visit or baby formula

Eligibility:

- Applicants must be a person with CF with demonstrated financial need
- Applicants are referred via CF clinic social worker, case manager, or other member of care team

Contact: info@cffamilyconnection.org



Eligibility:

- A CF patient, or family of a CF patient, who have experienced a hospital stay of at least 14 consecutive days within the last calendar year

Contact: 1-855-568-3273 /

Melissa@clairesplacefoundation.org

Healthwell Foundation – Cystic Fibrosis Treatment Fund

Services offered:

- Cost-share and premium cost assistance for indicated prescription drugs and biologics used by people with CF
- Financial assistance with vitamins and supplements

Eligibility:

- Applicants must be actively receiving treatment for CF in the US
- Have insurance that covers required medications
- Income falls within 500% of the Federal Poverty Level

Contact: 1-800-675-8416

Jeffery's House – Financial Assistance Grants

Services offered:

- Transplant housing grant
 - Applicants must be diagnosed with a condition that requires organ transplantation and travel to a Bay Area Hospital and be in need of lodging for the mandated 3-month post-transplant stay
- Living essentials allowance grant
 - Applicants must be diagnosed with a condition that requires organ transplantation and travel to a Bay Area Hospital

Eligibility:

- Eligibility criteria will depend on grant

Contact: 1-702-848-6042 / info@jeffreys-house.org

Living Breath Foundation – Financial Assistance Program

Services offered:

- Broad financial assistance to individuals or families with CF who are facing financial hardship

Eligibility:

- Applicants must have CF and be US citizens who reside in California or Arizona
- Must provide the first two pages of their tax return and current payroll stub
- Be able to provide a letter from your CF doctor confirming diagnosis of disease

Contact: 1-831-392-5283 /

LivingBreathFoundation@gmail.com

Miles for Cystic Fibrosis – Critical Needs Initiative

Services offered:

- Provides financial assistance in the form of grocery and/or fuel gift cards
- Monthly support is available up to \$1,000 per patient per calendar year

Eligibility:

- Applicants must be an active client of a CF Care Center located in Georgia or be a Georgia resident working with the CF Foundation COMPASS Program
- Be referred by your social worker, case manager, or another member of the healthcare team

Contact: 1-770-765-6508 / rrockhold@milesforcf.org

United States Government – Energy Bills Financial Assistance

Services offered:

- Programs that help pay for heating, cooling, or home weatherization depending on one's income
- Tip: Your energy service provider may have financial assistance programs based on income and/or medical needs to reduce your energy bills

Eligibility:

- Eligibility will vary depending on state guidelines. Please check [your state's eligibility criteria](#)

Contact: 1-844-872-4681

Vivian Lee Foundation – Family Assistance Program

Services offered:

- Childcare for sibling during clinic visits
- Loss of income for parents to attend clinic visits
- Loss of income for hospitalization (rent, utilities, etc.)
- Additional medical expenses after insurance
- Gas for to and from clinic visit

Eligibility

- Eligibility criteria will vary based on type of assistance, and amount of assistance will vary per family and per application
- Families must have verified CF status and may apply for assistance a maximum of six times per year

Contact: Send a [message through the website](#)



SCHOLARSHIPS

AbbVie– CF Scholarship Program

Services offered:

- An annual offering of \$3,000 to 40 scholars, with one undergraduate and one graduate student selected to receive an additional \$22,000 each

Eligibility:

- Applicants must be people with CF applying for an undergraduate or graduate program in the upcoming academic year
- Employees of AbbVie and their immediate family members are not eligible
- Applicants can be full-time or part-time students

Contact: 1-855-227-3493 / info@AbbVieCFScholarship.com

Bonnell Foundation – Education Scholarships

Services offered:

- An academic scholarship of up to \$2,500 (maximum of two years during an undergraduate degree)

Eligibility:

- Applicants must be a senior in high school or an undergrad at a community college, university, or trade school in the U.S.
- Have a CF diagnosis
- Have a minimum GPA of 2.5
- Be a U.S. Citizen

Contact: (248) 520-2329 / info@thebonnellfoundation.org

Boomer Esiason Foundation – Scholarship Program

Services offered:

- Financial assistance to students in the cystic fibrosis community who are pursuing higher education opportunities

Eligibility:

- Criteria varies depending on scholarship, but all applicants must, attend college or university in the US and have a CF diagnosis OR a sibling or parent with CF

Contact: 1-516-746-0077 / info@esiason.org

Living Breath Foundation – Scholarship Program

Services offered:

- Grants ranging from \$1,000 to \$5,000 for individuals with CF who are graduating from high school or continuing their higher education at a two-year, four-year, or trade school
- Academic scholarships may be used for any of the following: tuition, books, or any extra expenses which are directly correlated to attending school while having CF

Eligibility:

- Applicants must have CF and be US citizens who reside in California or Arizona
- Provide a copy of annual tuition, a letter of recommendation, and confirmation of CF diagnosis

Contact: 1-831-392-5283 /

LivingBreathFoundation@gmail.com

Patient Advocate Foundation – Scholarship Program

Services offered:

- National undergraduate, Virginia undergraduate, and graduate scholarships for students who have experienced, or are currently experiencing, cancer or chronic illness

Eligibility:

- Eligibility criteria varies depending on scholarship

Contact: 1-800-532-5274 /

scholarship@patientadvocate.org

Rock CF Foundation – Bowman Brothers Trade Scholarship

Services offered:

- Financial assistance of up to \$5,000 will be awarded to five individuals with CF who have received entrance into a trade program

Eligibility:

- Applicants must be 18 years of age or older
- Provide a letter from your CF center confirming diagnosis of disease
- Write a 2-part essay
- Submit an official or unofficial high school/college transcript
- Provide a breakdown of trade program tuition

Contact: emily@letsrockcf.org

Vertex– Vertex Foundation Scholarship

Services offered:

- Helps eligible students affected by CF, and their immediate family members or caregivers, afford college



- Scholarships of \$5,000 each are awarded to students pursuing two-year, four-year, or graduate degrees across the US or Canada

Eligibility:

- Applicants must be a US or Canadian citizen or legal permanent resident, and be diagnosed with CF or be an immediate family member or caregiver of someone with CF
- Applicants must have been admitted to a school for the upcoming academic year

Contact: 1-617-341-6100 / [online message platform](#)

United States Adult Cystic Fibrosis Association Inc.
– Education Scholarships

Services offered:

- Three academic scholarships for people with CF who are seeking artistic and/or educational degrees
- Financial assistance varies depending on scholarship, ranging from \$2,500-\$5,000

Eligibility:

- Eligibility criteria will vary depending on the academic scholarship one applies for

Contact: Email a representative at cfroundtable@usacfa.org



PHYSICAL & RECREATIONAL ACTIVITIES

Cystic Fibrosis Lifestyle Foundation – Recreation Grants for Felons

Services offered:

- Individuals with a criminal record who have CF, or a family member with the condition, may qualify for a \$500 recreation grant
- Examples: surfing, yoga, rock climbing, swimming, fitness, and more

Eligibility:

- Applicants must have CF or have a family member with CF
- Applicants will need to provide financial information for their household

Contact: Send a [message through the website](#)

Miles for Cystic Fibrosis – Recreation Grants BreatheStrong Grants

Services offered:

- The program provides grants for exercise equipment, organized fitness activities, and facility memberships for people with CF
- Grants do not exceed \$750/year

Eligibility

- Must be a child or adult with CF living in the United States

Contact: 1-770-765-6508 / info@milesforcf.org

Miles for Cystic Fibrosis – Recreation Grants

Loretta Morris Grants

Services Offered

- Provides financial assistance to individuals with CF who need help paying to participate in a physical fitness activities, like: swimming, horseback riding, dance, and golf
- Grants do not exceed \$750/year

Eligibility

- Preference is given to California residents

Contact: 1-770-765-6508 / info@milesforcf.org

Rock CF Foundation – Empower Program

Services offered:

- This program offers clients appropriate strength and conditioning coaching, as well as mindfulness programs, to help establish and reach relevant fitness levels

Eligibility:

- Contact the Rock CF Foundation for further details

Contact: info@letsrockcf.org

Vivian Lee Foundation – Salty Life Activity Grants

Services offered:

- Receive a grant of \$250 per CF patient per year to cover the cost of your child's activity (any sport, dance, gymnastics, camps, music, theater and academic clubs qualify)

Eligibility:

- Applicants must demonstrate that they have a CF diagnosis, and indicate which recreational activity they are seeking financial support with

Contact: Send a message through the website

INSURANCE, BILLING & LEGAL ASSISTANCE

The Assistance Fund – Cystic Fibrosis Copay Assistance Program

Services offered:

- Copay assistance for out-of-pocket costs for prescribed FDA-approved treatments

Eligibility:

- US citizen or permanent resident who has been diagnosed with CF
- Prescribed an FDA-approved treatment for CF
- Have prescription coverage for the prescribed treatment and meet financial eligibility criteria

Contact: 1-855-506-0629

CF Legal Information Hotline – Legal Resource

Services offered:

- Free and confidential hotline that can provide information about the laws that protect one's rights as a person with CF
- The experts at the hotline can provide information about health insurance, disability and government benefits, employment, and school
- The hotline is an information resource and does not provide legal advice or representation for callers

Eligibility:

- Anyone needing legal information about CF

Contact: 1-800-622-0385

Disability Rights Legal Center (DRLC)– Legal Assistance

Services offered:

- Free legal assistance to people with disabilities experiencing discrimination in violation of their civil rights
- For individuals with cancer, DRLC has a branch office called the Cancer Legal Resource Center (CLRC). CLRC provides information through its national telephone assistance line, outreach programs and community activities to educate and support cancer patients and their families on matters like maintaining employment through treatment, accessing healthcare, and taking medical leave

Eligibility:

- Eligibility criteria depends on legal service

Contact: 1-213-736-1031 / DRLC@theDRLC.org

GoodRX Health – Discounted Medications

Services offered:

- Company to help patients and families compare prices of needed medications and alert users to applicable discounts
- Individuals can use coupons at partnering pharmacies across the US to purchase life saving CF medications at a reduced cost

Eligibility:

- GoodRx cannot be used in conjunction with any US federal or state-funded program like Medicare or Medicaid, however it can be used as an alternative to your private or government-funded health insurance

Contact: 1-855-268-2822

My Patient Rights – Medical Advocacy Services

Services offered:

- Help for people who have been denied treatment, need medications, or have experienced delays

Contact: 1-916-531-3585

Patient Advocate Foundation – Case Management Program

Services offered:

- Investigation and identification of medical insurance coverage options
- Reviews of insurance benefits for mental health coverage
- Negotiations for payment plans, write-offs, and discounts with healthcare providers to resolve unpaid medical bills
- Coding and billing issues

Eligibility:

- Must be diagnosed or be getting tested for a health condition and be in active treatment, surveillance, or follow-up for the health condition
- Be a US citizen or permanent resident receiving treatment in the US or US territory

Contact: 1-800-532-5274



ADDITIONAL RESOURCES

[Cystic Fibrosis – Community Forum](#)

Services offered:

- Multiple community forums for people with CF to connect online and talk in real-time

Contact: Connect on social media @knowcf

[Cystic Fibrosis News Today – Cystic Fibrosis Online Publication](#)

Services offered:

- Online outlet publishing patient stories, diagnosis information, CF resources, up and coming science and research, and treatment insights

Contact: 1-800-936-1363 / info@bionews.com

[Genetic & Rare Diseases Information Center – Patient Organization Search Engine](#)

Services offered:

- Search engine providing people with CF and their loved ones with information about government, community, and not-for-profit programs

Contact: 1-888-205-2311

[Global Genes – News & Information Outlet](#)

Services offered:

- [Facebook group](#) for patients, caregivers, and advocates to have open conversations

Contact: 1-949-248-7273

Medical Assistance Tool – Biopharmaceutical Programs Search Engine

Services offered:

- A dedicated search engine that allows users to search for financial assistance resources through the various biopharmaceutical industry programs available for patients

Contact: 1-571-350-8643

National Organization for Rare Disorders (NORD) – Rare Disease Organization

Services offered:

- Nonprofit organization committed to sharing research, policy and action initiatives, and community events for various rare diseases, including CF

Contact: 1-617-249-7300

NeedyMeds – Financial Grant Search Engine

Services offered:

- Search engine showing 52 Diagnosis-based assistance programs/grants for people with cystic fibrosis in the US

Contact: 1-800-503-6897 / info@needymeds.org

Patient Worthy – Rare Disease Online Publication

Services offered:

- Online publication that provides relevant information to rare disease patients, caregivers, and advocates

Contact: 1-757-707-7842



INTERNATIONAL RESOURCES

CF Bridge of Hope – Patient & Family Resources

Services offered:

- Organization committed to improving international health equity by bringing select individuals with CF to the U.S. for interim treatment as a bridge solution while local resources in their native countries or regions are being established

Contact: 1-203-967-5949 / cfbridgeofhope@gmail.com

Cystic Fibrosis Canada – Programs & Resources

Services offered:

- Helpline
- Employment & financial resources
- Community Chapters program

Contact: 1-800-378-2233 / info@cysticfibrosis.ca

Cystic Fibrosis NZ – Patient Resources

Services offered:

- Organization committed to supporting and improving the quality of life for people with CF and their families in New Zealand
- The organization facilitates parent to parent support, provides vouchers and allowances during hospitalizations, and welfare assistance during hardship, among other services

Contact: 09-308-9161 / info@cfnz.org.nz

Cystic Fibrosis Trust (UK) – Grants

Services offered:

- Immediate financial help with home care, funeral costs, physical & mental wellbeing, transplant related costs, and education

Contact: 0300-373-1000 / helpline@cysticfibrosis.org.uk

CF Vests 4 Life – Medical Equipment for Providers

Services offered:

- Provision of life saving equipment and medications donated from CF patients in first world countries to people with CF in third world countries, where healthcare access and/or insurance coverage is lacking

Contact: marygrace@cf4l.com

Cystic Fibrosis Western Australia – Supports

Services offered:

- Adult travel and parking subsidy for medical visits
- Diabetes Sensor Subsidy
- Mental health out of pocket expenses for parents and caregivers
- Family support subsidy
- Employment and study subsidies

Contact: 08-6224-4100 / info@cfwa.org.au

Federación Latinoamericana de Fibrosis Quística – Latin American CF Organizations

Services offered:

- Organization that produces news and resources for people with CF in Latin America
- Access this site for a comprehensive list of CF organizations in Latin America

Contact: Send a message [via the website](#)

Miles for Cystic Fibrosis – Canadian Recreation Grant

Services offered:

- Assistance to Canadians with CF who are in need of direct financial assistance to afford recreational activities that have respiratory and psychosocial benefit
- Grants do not exceed USD \$750/year and will be paid directly to the company providing the activity

Eligibility:

- Must be a Canadian citizen and/or resident
- Applicants must answer questions regarding their current health and goals related to their chosen activity

Contact: 1-770-765-6508 / info@milesforcf.org

South African Cystic Fibrosis Association – Supports

Services offered:

- Support groups
- Mentorship

Contact: 083-285-5853 / info@sacfa.org.za



Our Mission

To be a global resource for the cystic fibrosis community while pursuing a cure through research, education, advocacy, and support.

Our Vision

To find a cure for cystic fibrosis while enhancing quality of life for the CF community.



Toll free 1.855.cfri.now (1.855.237.4669) | www.cfri.org

Updated: 2024