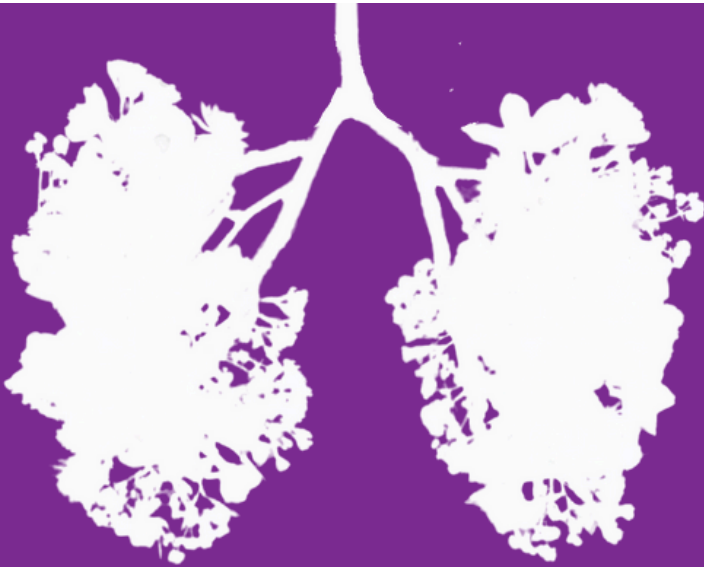


PATIENT ASSISTANCE RESOURCES



855-237-4669

cfri@cfri.org

www.cfri.org

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 Advisory 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

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CFRI COMMUNITY RESOURCES

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

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
- Support group for those with a late CF diagnosis
- Support group for people who cannot use modulators
- Conocimiento y Conexión: Meeting for the Spanish-speaking CF community
- Mindfulness sessions for the CF community

Wellness Classes for CF Patients & Families:

- Strength & Power Training
- U-Jam
- Core & Mobility
- Gentle Yoga & Mat Pilates
- GROOV3
- Cardio Barre
- POUND & POUND Unplugged

CFRI Community Retreats:

- CF Winter & 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, but may be eligible to receive free supplements and copay assistance
- 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:

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

Viatris — 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@viatris.com

Viatris — 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@viatris.com

FINANCIAL ASSISTANCE PROGRAMS

The Assistance Fund — CF 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
- Meet financial eligibility criteria based upon household income and size

Contact: 1-855-506-0629

Bonnell Foundation — Medical Assistance Program:

Services offered:

- Provides financial assistance that is not covered by insurance or any other program to help cover the costs of: 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:

- 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

BreatheStrongCF — Susan C. Burroughs Critical Needs Initiative:

Services offered:

- Provides financial assistance in the form of grocery and/or fuel gift cards

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
- Be experiencing a financial hardship as a result of reduction in income or increase in expenses

Contact: 1-770-765-6508 / grants@breathestrongcf.org



Claire's Place Foundation — Extended Hospital Stay Grant:

Services offered:

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

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
- Applicants must have a hospital professional (Doctor, Nurse, or Social Worker) submit a referral

Contact: 1-855-568-3273 /

Melissa@clairesplacefoundation.org

Cost Plus Drugs — Discounted Medications:

Services offered:

- Company aimed at lowering the price of certain drugs for consumers
- Consumers pay for the cost of manufacturing the drug, a 15% markup for each drug the company dispenses, and \$3 for pharmacy labor

Eligibility:

- Currently, prescriptions are only accepted by Capital Blue Cross, Rightway, and a few other prescription plans
- Cost Plus Drugs does not bill Medicare, whether you have a stand-alone Medicare Part D plan or a Medicare Advantage plan with prescription drug coverage. Medications therefore have to be paid for out of pocket.

Contact: Contact Cost Plus Drugs through the [online porta](#)



Cystic Fibrosis Family Connection — Emergency Fund:

Services offered:

- Financial assistance for expenses temporarily beyond a family's means
- Examples include: lodging for a transplant clinic visit, children's bedding, and baby formula
- Limit of \$500 per year per individual

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

Cystic Fibrosis Dreams Fund — General Financial Grants

Services offered:

- Provides general financial assistance through assistance grants to those struggling with the costs associated with cystic fibrosis, usually through direct payment

Eligibility:

- Applicants must be the parent or legal guardian of a minor child with CF or be an adult with CF
- Verification of bill for which you are requesting support

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

GoodRX Health — Discounted Medications:

Services offered:

- Compare prices of needed medications and find 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

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
- Living Essentials Grant

Eligibility:

- Applicants must be diagnosed with a condition that requires organ transplantation and travel to a Bay Area Hospital

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
- Applicants must have a demonstrated financial need and 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

Patient Advocate Foundation — Cop-Pay Relief

Services offered:

- Provides direct payment for co-pays, co-insurance, and deductibles for patients who need financial assistance.

Eligibility:

- Currently insured with a confirmed diagnosis, and have coverage for medication
- Must reside and receive treatment in the US
- Income at or below 400% of FPL with consideration for the Cost of Living Index and number in the household.

Contact: 1-866-512-3861

United States Government — Energy Bills Financial Assistance:

Services offered:

- Government programs that help pay for heating, cooling, or home weatherization depending on one's income level

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 for parents or CF patients
- Living expenses during illness or hospitalization or sickness
- Additional medical expenses after insurance

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 4 times per year (once every 90 days).

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

Dylan's Dream Foundation — Education Scholarships

Services offered:

- Academic scholarships awarded in amounts up to \$2,500 (based on upcoming registration costs)

Eligibility:

- Have a diagnosis of CF and have a demonstrated financial need
- Have been accepted at a college, university, or trade/vocational school
- Have a GPA of at least 2.0 at the time of application

Contact: (833) 483-9526 / info@dylansdream.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
- 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
- All applicants, across scholarships, must have been diagnosed with and/or been actively treated for a cancer or chronic disease within the past five years. Additionally, all applicants must have proof of an admissions letter

Contact: 1-800-532-5274 / scholarship@patientadvocate.org

The Rock CF Foundation — Bowman Brothers Trade Scholarship:

Services offered:

- Financial assistance of up to \$2,500 per recipient annually

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

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

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](#)



PHYSICAL & RECREATIONAL PROGRAMS

BreatheStrong CF — Exercise & Loretta Morris 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
- New applicants must submit a medical provider form indicating CF diagnosis

Contact: 1-770-765-6508 / grants@breathestrongcf.org

The Rock CF Foundation — Kicks Back Program:

Services offered:

- One pair of running shoes and registration into a race of the applicant's choice (race fees must not exceed \$100)

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 they have a CF diagnosis, and indicate which recreational activity they are seeking financial support with.
- There is a maximum of one request for assistance per year per family.

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

INSURANCE, BILLING & LEGAL ASSISTANCE

The Assistance Fund — CF 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
- Meet financial eligibility criteria based upon household income and size

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

Eligibility:

- Anyone needing legal information about CF

Contact: 1-800-622-0385

Disability Rights Legal Center — 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

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:

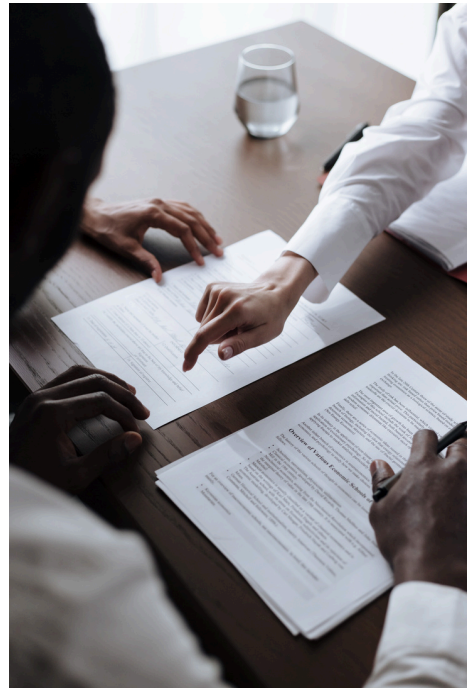
Services offered:

- 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:

- Applicants must be diagnosed or be getting tested for a serious health condition and be in active treatment, active 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 — CF 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:

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:

- Not-for-profit advocacy organization for individuals and families fighting rare and genetic diseases
- Offers news and information about relevant programs and resources for people with rare diseases

Contact: 1-949-248-7273

Global Genes — Facebook Community Group:

Services offered:

- Facebook group for patients, caregivers, and advocates to have open conversations about rare diseases

Medical Assistance Tool — Biopharmaceutical Industry Programs Search Engine:

Services offered:

- A dedicated search engine that allows users to search for financial assistance resources available to them, their loved ones or patients in their lives through the various biopharmaceutical industry programs available for patients

Contact: 1-571-350-8643

National Organization for Rare Disorders — 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

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

BreatheStrong CF — 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 or service

Eligibility:

- Must be a Canadian citizen and/or resident
- Applicants are encouraged to provide a letter of support from a healthcare provider, teacher, friend, or whomever can speak to why you are deserving of this grant.
- Applicants must answer questions regarding their current health and goals related to their chosen activity.
- New applicants must submit a medical provider form indicating CF diagnosis

Contact: 1-770-765-6508 / grants@breathestrongcf.org

CF Bridge of Hope — Medical Care:

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
- Parenting with CF 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
- TV rental subsidy for hospital stays
- Diabetes Sensor Subsidy
- Mental health out of pocket expenses for parents and carers
- Family support subsidy
- Employment and study subsidies

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

Federación Española de Fibrosis Quística — News & Research:

Services offered:

- The Federación Española de Fibrosis Quística is an organization that brings together and represents CF associations, comprising more than 4,000 members, throughout Spain
- The organization offers studies and publications, conducts advocacy and awareness campaigns, and funds research

Contact: 34-963-318-200 / info@fibrosisquistica.org

South African Cystic Fibrosis Association — Supports:

Services offered:

- Support groups
- Mentorship

Eligibility:

- Eligibility will vary depending upon the focus of each support group

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

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