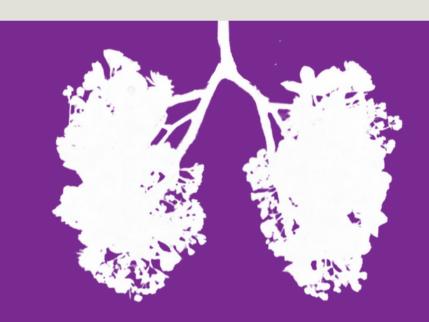
## PATIENT ASSISTANCE RESOURCES





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 was created with the assistance of CFRI's Diversity, Equity & Inclusion Committee, that supported the creation of this document for the purpose of making pharmaceutical, medical, financial, and recreational information 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 <u>CFRI Español</u>.

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

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### **TABLE OF CONTENTS**

CFRI Community Resources	<u>04</u>
<u>Pharmaceutical Assistance</u> <u>Programs</u>	<u>05</u>
<u>Financial Assistance</u>	<u>09</u>
<u>Scholarships</u>	<u>14</u>
Physical & Recreational Activities	<u>18</u>
Insurance, Billing & Legal Assistance	<u>20</u>
Additional Resources (Search Engines, Media)	<u>23</u>
International Resources	<u>25</u>







## CFRI COMMUNITY RESOURCES

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

#### <u>Psychological Support Programs & Classes (virtual):</u>

- Nationwide counseling support for people with CF and their families
- Caregiver support group for parents of children with CF, and 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
- Community 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



#### <u>Genentech – Pulmozyme Co-pay Program</u>

#### Services offered:

 Co-pay assistance to help cover additional out-ofpocket 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

#### <u>Gilead – Cayston Access Program</u>

#### 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 – Live 2 Thrive**

#### 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

## <u>Vertex Pharmaceuticals – Guidance & Patient Support (GPS)</u>

#### 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

#### <u>Viatris – Patient Assistance Program</u>

#### 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 (<u>Group 1 medicines</u>) / 1-888-417-5782 (<u>Group 2 medicines</u>) / customer.service@viatris.com



## FINANCIAL ASSISTANCE PROGRAMS

#### <u>Boomer Esiason Foundation – Patient & Family</u> <u>Assistance Programs</u>

#### **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 webiste

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

#### <u>Bonnell Foundation – Emily & Molly Bonnell</u> <u>Medical Assistance Program</u>

#### **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

### <u>United States Government – Energy Bills Financial</u> Assistance

#### Services offered:

 Programs that help pay for heating, cooling, or home weatherization depending on one's income

#### **Eligibility:**

Eligibility will vary depending on state guidelines.
 Please check your state's eligibility criteria.

Contact: 1-844-872-4681

### <u>Claire's Place Foundation – Extended Hospital Stay</u> **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

#### 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

#### <u>Cystic Fibrosis Family Connection – Emergency</u> 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

#### <u>Healthwell Foundation – Cystic Fibrosis Treatment</u> 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

#### <u>Vivian Lee Foundation – Family Assistance Program</u>

#### **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
- Expenses related to Covid-19 exposure or diagnosis
- · 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 applicat per family and per applicationion
- 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



#### **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

#### <u> Jeffery's House – Financial Assistance Grants</u>

#### 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
- <u>Living essentials allowance grant</u>
  - 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

#### <u>Living Breath Foundation – Financial Assistance</u> <u>Program</u>

#### 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

#### <u>Miles for Cystic Fibrosis – Critical Needs Initiative</u>

#### **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



### **SCHOLARSHIPS**

#### <u> Boomer Esiason Foundation – Scholarship Program</u>

#### 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

#### <u>Living Breath Foundation – Scholarship Program</u>

#### 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, fouryear, 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

#### <u>Patient Advocate Foundation – Scholarship</u> <u>Program</u>

#### 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

#### <u>Rock CF Foundation – Bowman Brothers Trade</u> <u>Scholarship</u>

#### 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

## <u>United States Adult Cystic Fibrosis Association Inc.</u> <u>– Education Scholarships</u>

#### 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

#### 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

#### <u>Bonnell Foundation – Education Scholarships</u>

#### 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



# PHYSICAL & RECREATIONAL ACTIVITIES

#### **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

#### <u>Vivian Lee Foundation – Salty Life Activity Grants</u>

#### 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 <u>message through the website</u>

#### 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 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 / <u>info@milesforcf.org</u>

## **Cystic Fibrosis Lifestyle Foundation** – <u>Recreation</u> **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

## INSURANCE, BILLING & LEGAL ASSISTANCE

#### <u>The Assistance Fund – Cystic Fibrosis Copay</u> <u>Assistance Program</u>

#### 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

#### <u>Cost Plus Drugs – Discounted Medications</u>

#### **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:**

- Prescriptions are only accepted by insurance for 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 through the online portal

#### **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

## <u>Disability Rights Legal Center (DRLC) – Legal</u> 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

#### <u>Patient Advocate Foundation – Case Management</u> <u>Program</u>

#### 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

#### **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



## ADDITIONAL RESOURCES

## <u>Genetic & Rare Diseases Information Center – Patient Organization Search Engine</u>

#### 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:

- News and information about relevant programs and resources for people with rare diseases
- <u>Facebook group</u> for patients, caregivers, and advocates to have open conversations

Contact: 1-949-248-7273

#### <u>Medical Assistance Tool – Biopharmaceutical</u> <u>Programs Search Engine</u>

#### Services offered:

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

Contact: 1-571-350-8643

#### <u>NeedyMeds – Financial Grant Search Engine</u>

#### 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

#### <u>Patient Worthy – Rare Disease Online Publication</u>

#### Services offered:

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

Contact: 1-757-707-7842

#### <u>Cystic Fibrosis News Today – Cystic Fibrosis Online</u> 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

## <u>National Organization for Rare Disorders (NORD) – Rare Disease Organization</u>

#### 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

#### <u>Cystic Fibrosis – Community Forum</u>

#### Services offered:

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



## INTERNATIONAL RESOURCES

#### Cystic Fibrosis Trust (UK) - Grants

#### Services offered:

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

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

#### **Cystic Fibrosis Western Australia – Support**s

#### 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

#### **Cystic Fibrosis Canada – Programs & Resources**

#### **Services offered:**

- Helpline
- Employment & financial resources
- Community Chapters program

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

## <u>South African Cystic Fibrosis Association – Supports</u>

#### Services offered:

- Support groups
- Mentorship

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

## <u>Miles for Cystic Fibrosis – Canadian Recreation</u> **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

#### <u>CF Bridge of Hope – Patient & Family Resources</u>

#### Services offered:

 Organization committed to improving international health equity by brining 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

## <u>Federación Latinoamericana de Fibrosis Quística – Latin American CF Organizations</u>

#### 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

#### <u>CF Vests 4 Life – Medical Equipment for Providers</u>

#### 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

#### <u>Federación Española de Fibrosis Quística – News &</u> 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

#### <u>Cystic Fibrosis NZ – Patient Resources</u>

#### 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

#### **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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