

## Resources for Patients with Cystic Fibrosis

This list is for patients and families living with cystic fibrosis (CF). Please ask any of the CF Care Team members if you have any questions. Keep in mind these programs are subject to change without us knowing. We update the information as we learn about changes.

### Education and General Information

#### Cystic Fibrosis Foundation (CFF)

<http://www.cff.org>

Phone: 1-800-344-4823

- Find a local chapter
- Find local CFF centers (Useful for travel)
- Great Strides Walk
- Volunteer
- Become an advocate
- Clinical trials
- Drug development pipeline
- Living with CF
- Treatments and research

#### CysticFibrosis.com

<http://www.cysticfibrosis.com>

- Community of patients and families
- Blogs
- Videos
- Recipes
- Fitness
- Clinical trials

#### Boomer Esiason Foundation

<http://www.esiason.org>

- What is CF
- Thriving with CF
- Team Boomer/Fund raising events
- CF news

#### CF Research Inc. <http://www.cfri.org>

- Fund research
- Educational and personal Support
- Spread awareness

#### National Newborn Screening and Genetics Resource Center

<http://genes-r-us.uthscsa.edu/resources/consumer/statemap.htm>

- The National Newborn Screening and Genetics Resource Center (NNSGRC)
- Information for every state
- Information and resources in the area of newborn screening and genetics

#### Enzymes and Vitamins

Enzyme and Vitamin programs change frequently. Often the maker of enzymes or the pharmacy that supplies them will give you free vitamins or supplements when you buy certain enzymes. Please read the details of each program carefully. Many programs require that you do not receive any state or federal aid money such as Medicaid or BadgerCare.

#### Aptalis: Makers of Zenpep® and Ultresa®

<http://www.allergan.com>

#### Patient Support

- **Aptalis Patient Assistance Program**  
<http://www.pparx.org>  
Financial help for certain Aptalis medicines for patients who have no prescription insurance/coverage  
**1-866-514-2442**
- **Live2Thrive**  
<http://www.live2thrive.org>  
Community of care and support for people with pancreatic insufficiency due to CF.
  - ❖ Nutrition support: Free vitamins and supplements
  - ❖ Interactive support/videos
  - ❖ Rewards program: earn points and turn them in for fun gifts

## **Zenpep®** <http://www.zenpep.com>

Product Profile and Medicine Guide

- Instant savings: save up to \$50 for every prescription of Zenpep®
- CF Patient Support Program. Help with co-pay and coverage of Zenpep® for eligible patients with commercial insurance coverage. **1-888-936-7371**

## **Abbvie: Makers of Creon®**

<http://www.creon.com>

- CFCareForward: Free vitamins, supplements, and co-pay rebate up to \$50/month with each Creon® purchase. You can pick up forms at the AFCH Pulmonary Clinic. Must send in a form with each shipment.
- Customer Service: **1-855-227-3493**

## **Abbvie Patient Assistance Foundation**

<http://www.abbviepaf.org>

**Phone: 1-800-222-6885**

## **Together Rx Access**

<http://www.togetherrxaccess.com>

**Phone: 1-800-444-4106**

Program developed by pharmaceutical companies to help patients and families find coverage and access to expensive medicines. Abbvie, maker of Creon®, is one of the participants.

## **Enteral Feeding Supplies**

### **The Oley Foundation**

[http://www.oley.org/Equipment\\_Exchange](http://www.oley.org/Equipment_Exchange)

Check website for a list of enteral feeding supplies. It includes equipment, tubing, bags, and formula that have been donated. If you see an item you want, call or email the volunteers. You can find contact information on the website.

## **Pharmacy Services**

Please check with your insurance since they may require that you receive your medicines from a specific pharmacy.

## **UW Health Specialty Pharmacy for Pulmonary**

<http://www.uwhealth.org> Website → Our Services → Other Services → Pharmacy Services → UW Specialty Mail Service Pharmacy

**Phone: 1-866-894-3784**

- Expert pharmacists available 24 hours a day
- Convenience: mail delivery to your door anywhere in United States
- Co-pay help: Medicine Prior Authorization Coordinators work to make sure that your out of pocket cost is as small as possible.

## **CF Services Pharmacy**

<http://www.cfservicespharmacy.com>

**Phone: 1-800-541-4959**

CF Services, a national mail-order pharmacy, can help patients get prescription medicines and provides personalized service, patient advocacy, patient education and reimbursement support to the CF community. CF Services runs many of the pharmaceutical patient assistance programs.

## **Foundation Care Pharmacy**

<http://www.foundcare.com>

**Phone: 1-877-291-1122**

Follow “Cystic Fibrosis Care” link provided in menu. Check Specials & Promotions.

Foundation Care often offers CF vitamins, hypertonic saline, and other items for free when specific medicines are filled through their pharmacy. Read each offer carefully as some are not available to those who receive state or federal aid such as BadgerCare or Medicaid.

## **Nebulized Medicines**

### **Pulmozyme® Access Solutions**

<http://www.PulmozymeAccessSolutions.com>

**Phone: 1-800-690-3023**

Website → Patient/Caregiver → Patient Assistance Programs.

- Benefits investigation
- Help with prior authorizations
- Pulmozyme® Co-Pay Card

**TOBI® <http://www.pharma.us.novartis.com>**

- PDF of patient information about TOBI®
- Patient help

**TOBI® Podhaler**

**<http://www.tobipodhaler.com>**

- PodCare+ a patient assistance program
- About TOBI® Podhaler, benefits and what to expect
- Taking TOBI® Podhaler, video on how to use device
- Pseudomonas information

**Hypertonic Saline**

**See Foundation Care Pharmacy under Pharmacy Services Section**

**Cayston® <http://www.cayston.com>**

- About Cayston®
- How to take Cayston®
- Cayston® access program
- Resource center
- Sign up for updates

**Patient Services Incorporated**

**<http://www.patientservicesinc.org>**

**Phone: 1-800-366-7741**

Co-payment help for patients with Cystic Fibrosis with pseudomonas (requiring treatment with **TOBI**) based on insurance, financial, and medical situation.

**Diabetes and CF Related Diabetes**

**Lilly Cares Program**

**<http://lillytruassist.com/Pages/AboutLillyCares.aspx>**

**Phone: 1-800-545-6962**

Lilly is the maker of Humalog®, Humulin®, and Glucagon®. If you qualify, your Lilly medicines will be shipped to your doctor's office free of charge for one year. To qualify you must have no prescription drug coverage, be a United States resident, and meet Lilly's household income guidelines.

**Patient Assistance Programs**

**NeedyMeds <http://www.needyMeds.org>**

NeedyMeds is an information source of patient assistance programs currently available with links to each program.

**Partnership for Prescription Assistance**

**<http://www.pparx.org>**

**Phone: 1-888-477-2669**

- Help finding the prescription drug coverage program that is right for you

**Cystic Fibrosis Foundation Patient Assistance Resource Center (PARC)**

**<http://www.cff.org/LivingWithCF/AssistanceResources>**

**Phone: 1-888-315-4154**

The CFF PARC assists families in getting the most benefit of your health care coverage, or to find programs that can help you pay for treatment.

**Healthwell Foundation**

Provides grants for people to help cover drug copays, deductibles and health insurance premiums as well as some vitamins, minerals, and nutritional supplements. You can receive a grant for up to \$15,000 to cover CF treatments and up to \$2,000 to cover CF vitamins and supplements. Anyone who is treated for CF in the US, has insurance that covers your CF approved medicine and meets the income guidelines (500% of the federal poverty level) can qualify. To apply:

**Call: 1-800-675-8416**

**Web: [www.healthwellfoundation.org/](http://www.healthwellfoundation.org/) (then click on "get assistance now")**

**Airway Clearance**

You will have time to talk with a respiratory therapist about the use of the vest during your clinic visits. Vest therapy is not used in children under 2 years old. You will need to check with your Durable Medical Equipment (DME) company to see which of the vests they are able to provide and service.

### **Hill-Rom (The Vest®)**

<http://www.thevest.com>

**Phone: 1-800-426-4224**

**Patients → Service and Support**

- Patient Assistance
- User Manual PDF

### **Electromed (SmartVest®)**

<http://www.electromed.com>

**Phone: 1-888-966-2525**

**Patients/Caregivers → SmartVest System**

- Compare devices
- In-home therapy
- Customer care and FAQ

### **Respirtech (The inCourage™ Vest)**

<http://www.respirtech.com>

**Phone: 1-800-793-1261**

- How it works
- Compare devices
- Customer care and FAQ

### **Housing and Transportation**

#### **Ronald McDonald House**

<http://www.rmhcmadison.org>

**2716 Marshall Court Madison, WI**

Ronald McDonald House is an option for patients under 18 years old and their families who are getting treatment at AFCH or other area hospitals.

- **If you have never stayed at Ronald McDonald House:** Please call AFCH Guest Depot for a referral at **608-890-8000**.
- **If you have stayed at Ronald McDonald House before:** You can call the house directly to ask about availability at **608-232-4660**.

#### **AFCH Patient Housing**

**Phone: 608-890-8000**

Help for families to find a place to stay in Madison while children are getting care at AFCH. Rooms at area hotels offered at reduced rates when referred through AFCH Patient Housing.

### **Transportation**

Help available for patients with medical assistance (MA) such as BadgerCare Plus Standard, BadgerCare Benchmark, and Wisconsin Medicaid. UWHC no longer provides cab vouchers for people in the Madison area.

**MTM Phone: 1-866-907-1493**

<http://www.mtm-inc.net/wisconsin-website/wisconsin-home>

- Patients and caregivers must schedule their own transportation
- Rides can be scheduled by phone or on-line
- Transportation for all scheduled clinic appointments must be made 2 business days in advance

### **Insurance-Wisconsin**

#### **Access Screening**

<http://access.wisconsin.gov>

- **Am I Eligible?**  
Online tool helps you figure out if you *might* be able to get help through programs like FoodShare, BadgerCare Plus, Medicaid, Child Care, Wisconsin Works (W-2), WIC, The Emergency Food Assistance Program, Wisconsin Home Energy Assistance Program, and the State Life Insurance Fund.
- **Apply for Benefits**  
Online application for the programs listed above.

#### **BadgerCare Plus**

<http://www.dhfs.state.wi.us>

**Phone: 1-800-362-3002**

**BadgerCare Plus → Become A Member/Children and Families**

All children under 19 years old, at all income levels, can enroll in BadgerCare Plus.

### **ForwardHealth Wisconsin**

**<http://www.dhs.wisconsin.gov/forwardhealth>**

**Phone: 1-866-908-1363**

- **Adult Cystic Fibrosis Insurance Plan Health Care Programs → Chronic Disease Program → scroll down to “Adult Cystic Fibrosis Program”**

Provides eligible adult patients with CF with certain inpatient and outpatient services related to CF, certain doctor services, certain lab and x-ray services, certain prescription medicines, certain home supplies.

### **Katie Beckett Program**

**Health Care Programs → Katie Beckett Program**

The Katie Beckett Program allows certain children who are residents of Wisconsin with long-term disabilities or complex medical needs, living at home with their families, to obtain a Wisconsin Medicaid card. Every state has a program like Katie Beckett although it may have a different name. Please check your state’s social services website for information.

### **Wish Granting Organizations**

#### **Make-A-Wish Foundation**

**Phone: 800-722-9474**

**Madison Office Phone: 608-252-4321**

**Website: [Wisconsin.wish.org/](http://www.wisconsin.wish.org/)**

Make-A-Wish Foundation is the largest and most well-known wish-granting organization in the United States. The foundation has granted more than 160,000 wishes to children with life-threatening illnesses in the United States since 1980, and even more worldwide. Make-A-Wish serves children between the ages of 2 ½ and 18.

#### **A Special Wish Foundation**

**Phone: 800-486-9474**

**Website: [www.spwish.org/](http://www.spwish.org/)**

The organization grants wishes to children with life-threatening illnesses. With 17 branches in the United States and one in Russia, A Special Wish has served children from birth to age 21 since 1982.

### **Children’s Wish Foundation International, Inc.**

**Phone: 800-323-9474**

**Website: [childrenswish.org/](http://childrenswish.org/)**

Children’s Wish Foundation has only one office but grants wishes to children worldwide. Since 1985, the foundation has been granting wishes to children with life-threatening illnesses from birth to age 18.

### **Kids Wish Network**

**Phone: 888-918-9004**

**Website: [kidswishnetwork.org](http://kidswishnetwork.org)**

The Kids Wish Network, was started in 1997, and grants wishes to children ages 3-18 who have life-threatening medical conditions. The Kids Wish Network also provides gifts to children’s hospitals at holiday times and helps fund funeral arrangements for children under the age of 21.

## **Legal**

### **CF Legal Information**

**<http://www.cff.org/livingwithcf/assistance/resources/cflegalhotline>**

**Phone: 1-800-622-0385**

**Email: [CFLegal@cff.org](mailto:CFLegal@cff.org)**

The CF Legal Information Hotline provides free information about the laws that protect the rights of those with CF. This includes questions about legal protections, insurance, federal and state benefits, and the Federal Medical Leave Act (FMLA).

### **Legal Action of Wisconsin**

**<http://www.legalaction.org>**

**Website → [Contact Legal Action \(Interactive Map with Contact Info\)](#)**

Legal Action of Wisconsin provides free legal help to low-income people who cannot afford legal help.

**ABC for Health** <http://www.safetyweb.org>

**Phone: 1-800-585-4222**

Advocacy and Benefits Counseling for Health, Inc. (ABC for Health), is a Wisconsin non-profit public interest law firm who provides health benefit counselors to help families make the best health coverage choices, apply for health coverage programs, deal with insurance companies, and challenge insurance claims.

## **Scholarships**

### **Cystic Fibrosis Foundation**

**Website:** <https://www.cff.org/Life-With-CF/Transitions/Managing-My-CF-in-College/Scholarships-and-Financial-Aid/>

The CF Foundation scholarship page lists many scholarship and education opportunities.

Scholarships given are based on financial need, academic achievement and leadership.

### **Boomer Esiason Foundation**

**Website:** <https://www.esiason.org/cf-living/scholarships>

BEF's scholarship program assists students who are working toward academic success while living with CF.

### **Abbie CF Scholarship**

**Website:** [www.abbiecf scholarship.com/](http://www.abbiecf scholarship.com/)

Abbie are the makers of Creon. This used to be called the CF Care Forward Scholarship.

### **Mandy Wagner Foundation**

**Scholarship Website:**

<http://www.mandywagnerfoundation.org/>

Scholarships for trade school, tech school, research grants - anything educational or to pursue a career or field for someone living with CF. Amounts will be \$500 and \$1000 to allow for as many recipients as possible.

Last updated January 2018. If your copy is more than 6 months old, please contact the UW CF Center as needed at **608-263-8555**.

Spanish version HFFY #7606

If you are a patient receiving care at UnityPoint – Meriter, Swedish American or a health system outside of UW Health, please use the phone numbers provided in your discharge instructions for any questions or concerns.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright ©1/2018. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#7243.