

NATIONAL AND INTERNATIONAL CF RESOURCES LIST

Improving Life with CF: A Primary Palliative Care Partnership

GEORGI19QI0

PIs: Anna Georgiopoulos, MD and Lara Dhingra, PhD

General Resources:

1. **Aimed Alliance:** <https://aimedalliance.org>
Provides education to both individuals and practitioners on patient rights to medical treatments.
2. **Attain Health:** <http://attainhealth.org/>
Includes resources for coaching, support, and educational services to promote the health of individuals with CF.
3. **Boomer Esiason Foundation:** <https://www.esiason.org/>
Promotes education, services, and research to enhance the quality of life for people with CF.
4. **CF Bridge of Hope:** <http://www.cfprojectinc.org/>
Provides resources and services for individuals with CF and their families living in areas with limited resources.
5. **Claire's Place:** <https://clairesplacefoundation.org/family-resource-support>
Provides support to families of a loved one with newly diagnosed CF; shares tools and provides guidance and assistance by connecting networks of families and young adults with CF.
6. **Cystic Fibrosis Engagement Network:** <https://engagecf.org>
Promotes advocacy and education for policies relating to providing care to individuals with CF.
7. **Cystic Fibrosis Foundation:** www.cff.org
 - a. Serves as the leading organization in CF research and advocacy.
 - b. Hosts the following:
 - i. Virtual events: CF BreatheCon, CF MiniCon and CF FamilyCon created by and for the CF community. These events are typically 1-2 days and provide an opportunity to connect, share and learn from others living with or affected by CF.
 - ii. CF Peer Connect: National peer mentoring program for individuals 16 years and older as well as family members and partners of those with CF.
 - iii. Compass: Personalized, one-on-one service that provides people living with CF, their families and their care teams with a partner in dealing with challenges related to life with CF.
 - iv. Cystic Fibrosis Legal Information Hotline: Email at CFLegal@sufianpassamano.com or call 1-800-622-0385.
8. **Cystic Fibrosis Lifestyle Foundation:** <https://cflf.org/>
Shares resources for engaging in an active lifestyle, and provides education related to the benefits of physical activity, for people with CF.
9. **Cystic Fibrosis News Today:** <https://cysticfibrosisnewstoday.com>

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Serves as a leading source of CF-related news that is geared toward individuals with CF and their caregivers.

10. **Cystic Fibrosis Research Inc.:** <https://cfri.org/>
Provides funding for CF-related research, education, and support for individuals with CF and their families.
11. **Cystic Fibrosis Trust:** <https://www.cysticfibrosis.org.uk/>
Provides funding for CF-related research and campaigns in order improve the quality of care for people with CF.
12. **Massachusetts General Hospital:**
 - a. ***Facing CF Book:*** Sher Y, Georgiopoulos AM, Stern TA (eds.) *Facing Cystic Fibrosis: A Guide for Patients and their Families*. Boston: Massachusetts General Hospital Psychiatry Academy, 2020.
 - b. Provides guidance for patients and their families on how to cope with CF on a day-to-day basis.
13. **Medline Plus:** <http://www.nlm.nih.gov/medlineplus>
Provides array of information regarding medical conditions including but not limited to medication, genetics, medical tests and a medical encyclopedia.
14. **National Organization of African Americans with CF:** <https://noaacf.org>
Provides education and raises CF awareness in the African-American community to help bring valuable resources, knowledge, empowerment and support to CF patients, families and professionals.
15. **Take a Breather Foundation:** <https://www.takeabreatherfromcf.org/>
Provides funding and support to individuals with CF and their families.
16. **The Bonnell Foundation: Living with Cystic Fibrosis:** <https://thebonnellfoundation.org/>
Provides emotional and financial support to parents who have a loved one with CF. The foundation offers college scholarships, medical assistance, and lung transplant grants to those affected by CF.
17. **United States Adult Cystic Fibrosis Foundation:** <https://www.cfroundtable.com/>
Provides information, news, support and outreach programs for adults with CF.

Financial Resources:

1. **Disability Benefits Help:** <http://www.disability-benefits-help.org/blog/long-term-disability-benefits-and-social-security-disability>

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Provides free disability evaluation for processing disability benefits.

2. **Employer Assistance and Resource Network on Disability Inclusion:** <https://askearn.org/state-vocational-rehabilitation-agencies/>
Helps individuals with disabilities meet their employment goals. Vocational rehabilitation agencies assist individuals in preparing for, obtaining, maintaining, or regaining employment.
3. **Family and Medical Leave Act:** <https://www.dol.gov/agencies/whd/fmla/faq>
Provides eligible employees up to 12 workweeks of unpaid leave per year, while maintaining group health benefits.
4. **HealthWell Foundation:** <https://www.healthwellfoundation.org/>
Provides financial options for underinsured individuals with chronic conditions like CF.
5. **InsureKidsNow.gov:** <http://www.insurekidsnow.gov>
Provides information for affordable healthcare options for children with CF and their families.
6. **O*NET Online:** <https://www.onetonline.org/>
Assists individuals in exploring career opportunities in various fields.
7. **Ticket to Work:** <https://yourtickettowork.ssa.gov/about/index.html>
Provides social security disability beneficiaries with opportunities and support needed to enter the workforce and maintain employment.
8. **U.S Department of Labor:** <https://www.dol.gov/>
Provides federal assistance for diverse employment issues/affairs.
9. **U.S. Small Business Administration:** <https://www.sba.gov/local-assistance/find?type=small%20Business%20Development%20Center&pageNumber=1>
Provides funding programs/local assistance to small businesses.
10. **U.S. Equal Employment Opportunity Commission:** <https://www.eeoc.gov/>
Provides legal support by enforcing laws that make it illegal to discriminate against a job applicant/employee due to disability status.

Therapeutic Resources:

1. **American Lung Association:** <https://www.lung.org/lung-health-diseases/lung-disease-lookup/cystic-fibrosis/treating-and-managing>
Provides information on lung disease, current treatment guidelines, and active research studies.
2. **Baby Steps Cystic Fibrosis:** <http://www.cysticfibrosisbabysteps.org.au/>

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Provides support to families of individuals with CF by connecting parents and sharing tools for treatment adherence and behavior modifications.

3. **Beam:** <https://beamfeelgood.com/home>
Provides training on physical activity classes for specific medical conditions like CF.
4. **CF Yogi:** <https://cfyogi.org/>
Provides specific yoga training for managing CF to improve breathwork and the union of body and breath.
5. **Coach Ed:** <http://www.coach-ed.org/>
Enables and supports CF patients to have healthy, active lifestyles and foster life beyond limitations of the disease. Program includes athletic sponsorships, scholarships, mentoring, adventure activities, and more.
6. **Cystic Fibrosis Reproductive and Sexual Health Collaborative:** www.cfreshc.org
Works to improve sexual and reproductive health knowledge, resources, and standards of care for women with CF through a collaborative of patients, clinicians and researchers.
7. **Scientific Registry of Transplant Recipients:** <https://www.srtr.org/>
Provides advanced statistical and epidemiological analyses related to solid organ allocation and transplantation for its timely use by public in support of the Department of Health and Human Services.
8. **United Network for Organ Sharing:** www.unos.org
Manages nation's organ transplant system under contract with federal government, bringing together professionals and volunteers for life-saving organ transplants every day.

International Organizations:

1. **Cystic Fibrosis Australia:** <https://www.cysticfibrosis.org.au/>
Provides support and services to families of individuals with CF, information on advocacy, and research specific to CF.
2. **Cystic Fibrosis Europe:** <https://www.cf-europe.eu/>
Provides support and services to families of individuals with CF, prioritizing patient-centered research and patient perspectives to defend the interests of people with CF.
3. **Cystic Fibrosis Foundation of Israel:** http://cff.org.il/en/?page_id=409
Provides support and services to families with CF living in Israel and assists in procuring medical equipment to ensure appropriate treatment for patients with CF.
4. **Cystic Fibrosis Western Australia:** <https://www.cfwaw.org.au/>

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Provides support and services to families of individuals with CF, information on advocacy, and research specific to CF.

5. **European Cystic Fibrosis Society:** <https://www.ecfs.eu/>

Provides a platform for scientific and clinical professionals to connect and share high-quality research, education, and care specific to CF. Holds annual conferences and encourages poster presentations promoting young researchers.