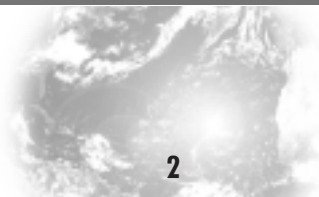


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Basic Information about Cystic Fibrosis

Cystic Fibrosis Research, Inc. Independent, non-profit volunteer organization dedicated to fund CF research, provide educational & personal support and increase awareness of CF. Knowledgebase.	http://www.cfri.org
Cystic Fibrosis Foundation Resource information about cystic fibrosis.	http://www.cff.org
Cystic Fibrosis Center at Stanford A guide to living with CF.	http://cfcenter.stanford.edu
National Library of Medicine and National Institute of Health. Medline Plus - Cystic Fibrosis information and links.	http://www.nlm.nih.gov/medlineplus/cysticfibrosis.html
United States Adult Cystic Fibrosis Association - USACFA – Publishers of CF Roundtable.	http://www.usacfa.org/
Cystic Fibrosis from Wikipedia, online encyclopedia.	http://en.wikipedia.org/wiki/Cystic_fibrosis
About.com has guide sites and articles about CF by non-professionals.	http://search.about.com/fullsearch.htm?terms=cystic+fibrosis&PM=59_0100_S
KidsHealth for Parents, CF topics for parents and caregivers.	http://www.kidshealth.org/parent/medical/lungs/cf.html
A popular portal site providing access to Internet sources in health and medicine.	http://www.lib.uiowa.edu/hardin/md/cysticfibrosis.html
Cystic Fibrosis. A one-stop web site for more information about CF and additional links.	http://www3.nbnet.nb.ca/normap/CF.htm



Cystic Fibrosis Research

CFRI funded research and post-doctoral fellowship program.

<http://www.cfri.org>

CF research news.

<http://www.cff.org/research/ClinicalResearch/>

To encompass a broad range of studies aimed at understanding the structure and function of the human genome and its role in health and disease.

<http://www.genome.gov/10001213>

National Jewish Medical and Research Center
Global Leader in Lung Allergic and Immune Diseases.

<http://www.njc.org>

Cystic Fibrosis: What Causes It?

<http://www.ygyh.org/cf/cause.htm>

Genetics and Cystic Fibrosis

Cystic Fibrosis Mutation Database is devoted to the collection of mutations in the CFTR gene. The specific aim of the database is to provide CF researchers with up to date information about individual mutations in their CFTR gene.

<http://www.genet.sickkids.on.ca>

Genetics Home Reference.

<http://ghr.nlm.nih.gov/condition=cysticfibrosis>

National Human Genome Research Institute –
National Institutes of Health.

<http://www.genome.gov/page.cfm?pageID=10001213>

Comprehensive CF medical summary.

<http://www.genereviews.org>

Large resource on cystic fibrosis.

<http://www.cysticfibrosismedicine.com>

Online Mendelian Inheritance in Man. A catalog of human genes and genetic disorders.
Biotechnology information.

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM>

GeneCare Medical Genetics Center-Patient
Information On CF Testing.

<http://www.genecare.com/cf.html>

Quest Diagnostics – CF Testing.

<HTTP://WWW.QUESTDIAGNOSTICS.COM/HCP/TOPICS/CFCOMPLETE/CFCOMPLETE.HTML>

Cystic Fibrosis mutation database.

<http://www.genet.sickkids.on.ca/cftr/app>

John Hopkins Medical Institutions.

<http://www.hopkinsmedicine.org/cfgenotyping/mdb.htm>

Diagnosis and Symptoms

Ambry Genetics® - Comprehensive, reliable, and state-of-the-art DNA diagnostic testing.	http://ambrygen.com/
Laboratories offering clinical testing.	http://www.genetests.org/query?testid=2220
The Sweat Test.	http://www.cff.org/AboutCF/Testing/SweatTest/
Trypsin Test.	http://www.labtestsonline.org/understanding/analytes/trypsin/test.html
Trypsinogen Test.	http://www.labtestsonline.org/understanding/analytes/trypsinogen/test.html
Prenatal Diagnosis-CF and Pregnancy.	http://www.ucsfhealth.org/childrens/medical_services/preg/prenatal/conditions/cystic/signs.html
Cystic Fibrosis Carrier Testing.	http://www.acog.org/from_home/wellness/cf001.htm

Screening Information

National Newborn Screening and Genetics Resource Center web site.	http://genes-r-us.uthscsa.edu/
Newborn Screening.	http://www.cff.org/AboutCF/Testing/NewbornScreening/
To improve the lives of babies by working to prevent disabilities through newborn screening.	http://www.savebabies.org
CF Carrier Testing.	http://www.medem.com/medlb/article_detailb.cfm?article_ID=ZZJIE8XUUSC&sub_cat=2005
CF Testing if both partners are carriers.	http://www.medem.com/medlb/article_detailb.cfm?article_ID=ZZQRC4JUSC&sub_cat=2005

CF Treatments

Drug Digest-Treatment Options-Conditions and Treatments.	http://www.drugdigest.org/DD/HC/Treatment/0,4047,851,00.html
Mayo Clinic.	http://www.mayoclinic.com/health/cysticfibrosis/DS00287/DSECTION=8
CF - Treatment Pulmonology Channel.	http://www.pulmonologychannel.com/cf/treatment.shtml
Overview by Web MD.	http://www.webmd.com/hw/health_guide_atoz/hw188735.asp
Glutathione System Dysfunction and Glutathione Augmentation Therapy.	http://members.tripod.com/uvicf/gsh/gshprospects.htm

Alternative Treatments

Treatments to address and enhance the quality of life for the person with cystic fibrosis.	http://www.cystic-fibrosis-symptom.com/alternatives.htm
University of Maryland Medical Center.	http://www.umm.edu/altmed/ConsConditions/CysticFibrosisic.html#Alternative
Health and Age.	http://www.healthandage.com/html/res/com/ConsCondition

CF Medical News

International Medical Directory.	http://cellscience.com/cfmain.html
Doctor's Guide to Medical and Other News. The latest medical news and information for patients or friends/parents of patients diagnosed with Cystic Fibrosis.	http://pslgroup.com/CF.HTM#News
PubMed — Latest publications and abstract articles regarding cystic fibrosis. National Library of Medicine.	http://www.ncbi.nlm.nih.gov/entrez/query.fcgi
Cystic Fibrosis Medicine has been set up with the aim of providing free information to professionals who treats CF. An open access (PUBLIC) section is also available to both patients and family.	http://www.cysticfibrosismedicine.com
Health Encyclopedia: CF-Symptoms, treatment and prevention.	http://www.healthscout.com/ency/68/222/main.html
BBC-Health Conditions-CF in the United Kingdom.	http://www.bbc.co.uk/health/conditions/cystic1.shtml
CF: Lung and Airway Disorders: Merck Manual Home Edition online medical library.	http://www.merck.com/mmhe/sec04/ch053/ch053a.html
Healthopedia.com — Health encyclopedia.	http://www.healthopedia.com/cystic-fibrosis/

CF Support

Cystic-L is an online service dedicated to the exchange of information and support specific to Cystic Fibrosis.	http://www.cystic-l.org/index.htm
Conncoll International Cystic Fibrosis Support Group. To give support to those involved with the disease and to provide a forum for the discussion of topics relative to Cystic Fibrosis.	http://cf.conncoll.edu/index1.html
Online support for people with CF, their families and caregivers.	http://www.cysticfibrosis.com

A place to share information and seek support if you are the parent or caregiver of an infant or toddler with Cystic Fibrosis.	http://health.groups.yahoo.com/group/CF_Infants_Toddlers/
Jerry Cahill Cystic Fibrosis Podcast.	http://www.jerrycahill.com
An Email Support Group for young people, ages 12-40ish, living with the challenges of Chronic Lung Conditions.	http://health.groups.yahoo.com/group/YOUNGLUNG/
Heroes of Hope – Living with CF.	http://www.heroesofhope.gene.com/heroesofhope/
cForward.net – CF resources and support.	http://www.cforward.net/
The Well Spouse Foundation. Provides support and information to the well spouses of the chronically ill, and educates human services professionals and the public about the needs of spousal caregivers and their families.	http://www.wellspouse.org
A support Group for anyone dealing with Cystic Fibrosis and Liver Disease, or those dealing with CF and GI issues.	http://health.groups.yahoo.com/group/CF_LiverDisease/
Support group with religious affiliations.	http://health.groups.yahoo.com/group/CF_4_Christians/
Online community about Cystic Fibrosis. Everybody can register post and reply in the forums.	http://www.cf-talk.invisionzone.com
CF Solutions, Inc.	http://www.cf-solutions.org/adultpage.htm
National CF Awareness Committee - support for the individuals and their families who struggle with this disease.	http://www.cfawareness.org
Breathing Room - The Art of Living with CF.	http://www.thebreathingroom.org
Healingwell – Community, Information, Resources on Diseases, Disorders and Chronic Illness.	http://www.healingwell.com/pages/Cystic_Fibrosis/
A place to discuss issues specific to raising children who have been diagnosed with cystic fibrosis... a place for parents of children with cf to come to for support and information.	http://groups.yahoo.com/group/cfparents
Starbright. Innovative media based programs to help children and teens enhance their quality of life.	http://starbright.org/
Parenting children with health issues.	http://www.parentingchildrenwithhealthissues.com/index.html

An online support group for cystic fibrosis.	http://www.dailystrength.org/support/Lungs_Respiration/Cystic_Fibrosis/
Online forum to promote research, share experiences, and synthesizing information with the objective to improve the conditions of cystic fibrosis.	http://health.groups.yahoo.com/group/sharktank/
A non-medical group interested in exploring the possibilities of crataegus and it's value as a therapy.	http://health.groups.yahoo.com/group/crataegus/
Bring people facing similar life challenges together to share their stories, advice and support.	http://www.dailystrength.org/component/option,com_resources/task,res/cat_id,108/cid,168/
CF Message board.	http://www.tdl.com/~barky/cfboard/wwwboard.html

CF Related Diabetes and Nutrition

American Diabetes Association (ADA).	http://www.diabetes.org
American Dietetic Association (ADA).	http://www.eatright.org/
Joslin Diabetes Center. Research, Treatment, Patient and Professional Education.	http://www.joslin.harvard.edu
Juvenile Diabetes Research International Foundation.	http://www.jdf.org
Dia-Log.com-free online Diabetes logbook.	http://www.dia-log.com
National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK). Medical information about research and clinical trials.	http://www.niddk.nih.gov/

Pulmonary and General Medicine Resources

American Association for Respiratory Care.	http://www.aarc.org
American Lung Association National Office.	http://www.lungusa.org
NIH, National Institute of Health is the nation's medical research agency-making important medical discoveries that improve health and save lives.	http://www.nih.gov
National Library of Medicine, part of National Institute of Health, free access to MEDLINE "search MEDLINE free" under Hot Topics.	http://www.nlm.nih.gov
Medical information on pulmonary topics, including cystic fibrosis.	http://respiratorycare.medscape.com

Vestibular Disorders Resources (Inner Ear and Balance Problems)

Vestibular Disorders Association "VEDA". Non-profit organization that serves people with vestibular disorders and the health professionals who treat them.

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

Vestibular Balance Disorders.

http://www.medicinenet.com/vestibular_balance_disorders/article.htm

Organ Donation and Transplantation Organizations

United Network for Organ Sharing. To improve the effectiveness of human organ donation, procurement, distribution and transplantation.

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

Links to other Organ Donation and Transplant sites.

<http://www.o-o-t-a.org/>

Children's Organ Transplant Association (COTA) ensures that no U.S. citizen is denied life saving transplant due solely to lack of funds.

<http://www.cota.org>

National Foundation for Transplants.

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

Second Wind Lung Association, Inc. Dedicated to support and education of lung transplant candidates, recipients, friends, family and the public, regarding the Need for organ donation and benefits of transplantation.

<http://www.2ndwind.org/>

Devoted to improving the quality of life for lung transplant recipients, lung surgery candidates, people with related pulmonary concerns and their families.

<http://www.secondwindstl.org>

Website with transplant information.

<http://www.transplantliving.org>

London Health Sciences Centre. Multi-Organ Transplant Program.

<http://www.lhsc.on.ca/cgi-bin/search?filter=transplant>

California Transplant Donor Network – Organ and Tissue Donations.

<http://www.ctdn.org>

The Health Resources Administration & Department of Health and Human Services.

<http://www.organdonor.gov>


Novartis – Comprehensive information on transplantation.

<http://www.transplantsquare.com>

TransWeb. All about Transplantation and Donation.

<http://www.transweb.org/default.htm>





Transplant Recipients International Organization.	http://www.trioweb.org
New England Organ Bank (U.S.).	http://www.neob.org/
Created by people with people with Cystic Fibrosis (CF) to educate people about the disease and raising awareness of organ transplantation.	http://www.friends4life.org.uk
To provide information, direct you to other resources and to give you a place to discuss and ask questions about the transplant process in general.	http://www.transplantbuddies.org
"Taking Flight" - Recipients of lung transplant share their stories of success.	http://www.trafford.com/robots/02-0497.html
	http://groups.msn.com/TransplantSupportLungHeartLungHeart/

Fertility Information

Natural child bearing and child rearing. To assist all parents in their life long quest to be the best parent they can be.	http://www.yourtreeoflife.com
A guide for men with CF.	http://www.cysticfibrosismaleinfertility.com
Cystic Fibrosis and infertility.	http://www3.nbnet.nb.ca/normap/cfinfertility.htm

Pharmacies

CF Pharmacy. HHCS Health Group, Florida - dedicated to serving person's with CF as well as their families.	http://www.cfpharmacy.com
CF Services Pharmacy.	http://www.cfservicespharmacy.com/
Pharmacare specialty pharmacy - dedicated to helping patients manage their medication program effectively and live life to the fullest.	http://www.stadtlander.com
Vistapharm-healthcare company that specializes in delivering pharmaceutical and nutritional products that offer significant clinical benefit at a reasonable price.	http://www.vistapharm.com
Freedom Pharmacy specializes in the care and treatment of chronic disease. The circle of care programs involve the patient, the family, the doctor and the pharmacist.	http://www.freedommeds.com
Pharmaceutical Research and Manufacturers of America.	http://www.phrma.org/

Pharmaceuticals & Patient Assistance Programs

Digestive Care, Inc., makers of PANCREARB®
Treatment for pancreatic enzyme deficiency.
Offers Assistance, Starter, and First Start Programs,
helping those in need.

<http://digestivecare.com>
http://digestivecare.com/patient_programs.htm

Novartis Pharmaceuticals Corporation's Patient Assistance Program (PAP). Makers of TOBI® provide assistance to patients experiencing financial hardship.

<http://www.pharma.us.novartis.com>
<http://www.pharma.us.novartis.com/novartis/pap/pap.jsp>

Genentech, manufacturers of Pulmozyme®, offers Access to Care Foundation and the Genentech Endowment for CF expanding patients' access to Pulmozyme therapy.

<http://www.gene.com>
<http://www.gene.com/gene/about/community/access.jsp>

Axcan Scandipharm, makers of Ultrase®, offers CareFirst, Comprehensive care and Rx Cost Reduction programs to ease the financial burdens of patients.

<http://www.axcanscandipharm.com>
<http://www.axcanscandipharm.com/productsunitedstates.php?lang=1>

Solvay Pharmaceuticals, makers of Creon®, treatments for pancreatic enzyme deficiency.

<http://www.solvaypharmaceuticals-us.com>
<http://www.solvaypharmaceuticals-us.com/patients/patientassistanceprogram/0,,7438-20,00.htm>

Hill-Rom, Inc., maker of the Vest™, airway clearance system used to help clear excess mucus from lungs. The Vest Foundation.

<http://www.thevest.com>

ElectroMed, Inc., Smart Vest®, High frequency chest wall oscillation.

<http://www.electromed-usa.com>
<http://www.electromed-usa.com/services.html>

Dymedso, Inc., maker of the Frequencer™, a digitally controlled electro-acoustical transducer device.

<http://www.dymedso.com>

SourceCF®, with comprehensive family of products, including the eFlow®.

<http://www.sourcecf.com>

Specialists in aerosol delivery and research.

<http://www.pari.com>

Med Solutions, a non-profit, that will assist qualifying individuals with medications through patient assistant programs sponsored by pharmaceuticals.

<http://www.freemedandsolutions.com/>



Financial Assistance Information

Boomer Esiason Foundation – Basic CF information, fundraising events and assistance.

<http://www.esiason.org>

Devoted to alleviating the myriad of devastating consequences suffered by the CF afflicted and their families.

<http://www.r4stars.org>

Cystic Fibrosis Reaching out Foundation. Enhancing life for patients and families with CF.

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

Foundation goals are to educate, raise awareness and provide financial assistance to families in need.

<http://www.milanfoundation.org>

National Transplant Assistance Fund (NATF). Provides vital transplant and donor organ information, financial assistance, fundraising advice and trusteeship.

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

To ease the heavy financial burdens placed on CF patients and their families and to provide needed information. New Jersey.

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

Valuable financial assistance information and contacts for individuals, local, national and international.

<http://www.nonprofitexpert.com/states/ca.htm>

Cody Dieruf Benefit Foundation - raise awareness of CF and offer financial and emotional support to local children and young adults with CF and their families.

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

Scholarship Information

Boomer Esiason Foundation. Raises money for CF research and provide scholarships.

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

Mission is to provide an opportunity for young adults with CF to further their education at a college or vocational school.

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

Elizabeth Nash Foundation - a specific emphasis on efforts that improve the lives of those affected by cystic fibrosis.

<http://www.elizabethnashfoundation.org>

Fast WEB Scholarship Search.

<http://www.fastweb.com>

Federal Student Aid - FAFSA.

<http://www.fafsa.ed.gov/>

Individual Education Accommodations

504 Plan FAQ - Frequently Asked Questions.	http://www.chtu.org/504.html
Section 504 - civil rights law that prohibits discrimination against individuals with disabilities. Section 504 ensures that the child with a disability has equal access to an education.	http://www.wrightslaw.com/info/sec504.index.htm
504 plans and IDEA (Individuals with Disabilities Education Act) provisions and additional links.	http://www.adprima.com/specialed.htm
Section 504 of the Rehabilitation Act and the Americans with Disabilities Act.	http://www.specialchildren.about.com/od/504s/f/504faq1.htm
IEPs vs. 504 Plans.	http://www.slc.sevier.org/iepv504.htm
A Guide to the Individualized Education Program.	http://www.ed.gov/parents/needs/speced/iepguide/index.html
Individual Education Program article.	http://www.kidshealth.org/parent/positive/learning/iep.html
Some tips on writing effective IEPs.	http://specialed.about.com/od/iep/Individual_Education_Plan.htm
Other links and resources for IEPs.	http://www.familyvillage.wisc.edu/education/iep.html

Disability Rights

Disabilities Rights Education and Defense Fund (DREDF).	http://www.dredf.org
United States Equal Employment Opportunity Commission (EEOC).	http://www.eeoc.gov
To expand opportunities and enhance the quality of life of children and adults with disabilities and their families based on the concept of parents helping parents.	http://www.pacer.org
National Dissemination Center For Children With Disabilities.	http://www.nichcy.org
Disability Resources Monthly Guide to disability resources on the internet.	http://www.disabilityresources.org/



International Sites

International Directory of CF charities.	http://www.cellscience.com/cfcharities.html
Canadian Cystic Fibrosis Foundation.	http://www.cysticfibrosis.ca/
Cystic Fibrosis Worldwide — Publications and newsletter in various languages.	http://www.cfwv.org
The European Cystic Fibrosis Society provides a European forum where clinicians and scientists can meet, present and discuss the latest findings concerning the disease.	http://www.ecfsoc.org/
CF Trust working to improve the lives of people with CF raises the profile of CF and fund research into a cure.	http://www.cftrust.org.uk/
Cochrane CFGD Group.	http://www.cochrane.org/reviews/en/topics/55.html
The Cystic Fibrosis Association is an incorporated society providing membership for regional groups, businesses and individuals working together in support of people with cystic fibrosis and their families.	http://www.cfnz.org.nz/
Cystic Fibrosis Australia assists member organizations to achieve common objectives by developing national education programs and collecting and distributing information about Cystic Fibrosis (CF) at national and international levels.	http://www.cysticfibrosis.org.au/
Cystic Fibrosis Foundation of Israel.	http://www.cff.org.il/
Cystic Fibrosis in Spanish - Página de J. M. Pulido	http://www.geocities.com/HotSprings/2677/
Federación Española contra la Fibrosis Quística.	http://www.fibrosis.org/

Travel Resources

Access-Able travel source database. Information to travelers with disabilities.	http://www.access-able.com
Online translations between English & French, German, Italian, Portuguese & Spanish.	http://www.babelfish.com
Angel Flight West & Angel Flight America - arranges free air transportation in response to health care and other compelling human needs.	http://www.angelflight.org http://www.angelflight.org/flights/

Miscellaneous

U.S. Commission on Civil Rights.	http://www.usccr.gov
Learning about resilience, thriving and how to gain strength from adversity.	http://www.thrivenet.com
New Day Wellness is a non-profit organization providing health and wellness coaching to people with CF.	http://www.newdaywell.org/
Find the right doctor in your area.	http://www.doctordirectory.com/doctordirectory/hospital/state.aspx
Computer dictionary for Internet and Web definitions, terms and phrases.	http://whatis.techtarget.com/
Resource for people living with CF. Personal management tools to track important health measures on a daily basis.	http://www.mycysticfibrosis.com
Angel Food Ministries is a non-profit, non-denominational organization dedicated to providing grocery relief to communities throughout the United States.	http://angelfoodministries.org/
A family's story about the struggle with CF.	http://www.faithandawareness.com
Doula care and childbirth education. Empowering women in making choices.	http://www.doulacare.ca/index.htm
A national grassroots network of families and friends which advocates for health care services and provides information for families with children and youth with special health care needs.	http://www.familyvoices.org/
Comprehensive list of websites including international sites.	http://www.kumc.edu/gec/support/cystic_f.html
Global network of people who want to work together to change their communities and the world.	http://www.idealists.org/
Ask any question; Thousands volunteer subject experts are here to answer your questions.	http://www.allexperts.com
6500 Red Roses – A photo project to fund CF research and find a cure.	http://www.6500redroses.com



Humor

The Association for Applied and Therapeutic Humor.	http://www.aath.org/
Good, Clean Funnies List. 5 days a week.	http://www.gcf.net
Comics from newspapers.	http://www.kingfeatures.com
Official Peanuts (Charles Schulz) website.	http://www.snoopy.com
Best Searchers – Humor websites.	http://www.bestsearchers.com/best-websites/humor-jokes.html#Jokes
Jokes & Humor websites.	http://swcbc.org/humor.html