

The Guide

Resources for the CF Community

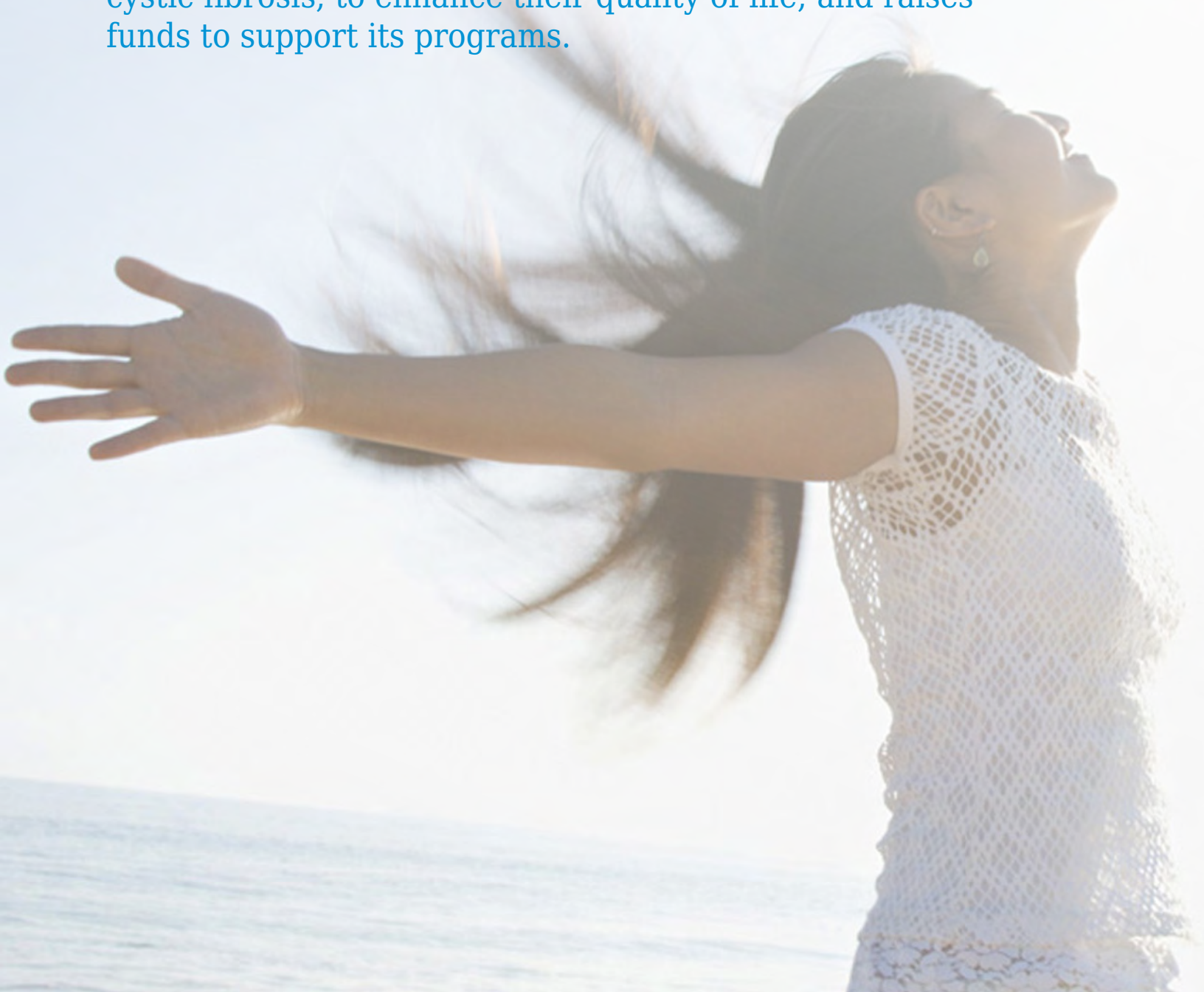


Cystic Fibrosis
Canada

Breathing life into the future®

What is Cystic Fibrosis Canada?

Cystic Fibrosis Canada (formerly the Canadian Cystic Fibrosis Foundation) is a national health charity established in 1960, with 50 volunteer chapters across Canada. Our mandate is to help people with cystic fibrosis, principally by funding cystic fibrosis research and by supporting high quality clinical and transplant care at the 42 specialized CF clinics and five transplant centres in Canada. Cystic Fibrosis Canada also provides educational materials for the cystic fibrosis community and the general public; undertakes advocacy initiatives with, and on behalf of Canadians with cystic fibrosis, to enhance their quality of life; and raises funds to support its programs.



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Introduction

Services and resources, available to individuals with cystic fibrosis (CF) and their caregivers, vary between provinces and can be difficult to find or identify.

Cystic Fibrosis Canada provides *The Guide: Resources for the CF Community* to members of the CF community, including CF clinics and Cystic Fibrosis Canada chapters, as a source of information for persons with CF and their families. *The Guide* is intended to:

- outline services, programs, and resources available in each province and across the country;
- assist persons with CF and their families who may be travelling or moving between provinces; and
- identify areas for advocacy initiatives to improve access to services and resources for persons with cystic fibrosis.

The Guide is comprised of four parts. The first outlines information on services and resources provided by the federal government and national agencies; the second outlines clinical and community services, programs, and resources offered on a provincial or regional basis; the third provides transplant resources; and the fourth lists contact information for Cystic Fibrosis Canada chapters and Adult CF Committee members.

Cystic Fibrosis Canada is grateful to the members of the Adult CF Committee and CF clinic team members for their assistance in providing, and reviewing, the information in *The Guide*. This document is updated on a regular basis (information in this *Guide* was sourced up to November 2011); however, given the shifting nature of the programs outlined in *The Guide*, we assume no responsibility for any inaccuracies found in the text. Please contact Cystic Fibrosis Canada if you discover any errors or omissions.

We are pleased to discuss any questions not covered in *The Guide*, or to provide further information. Inquiries can be directed to:

Cystic Fibrosis Canada
2221 Yonge Street, Suite 601
Toronto, Ontario M4S 2B4
Tel: 416-485-9149
Toll free: 1-800-378-2233
Fax: 416-485-0960
E-mail: info@cysticfibrosis.ca
Web site: www.cysticfibrosis.ca

Canada-wide Resources

Canada Health Act

The *Canada Health Act* governs health care across Canada, but the provincial and territorial governments are responsible for the management, organization and delivery of health services for their residents. Provincial and territorial governments must follow the guidelines for health care and coverage as outlined in the *Act* in order to qualify for funding from the federal government.

<http://www.hc-sc.gc.ca/hcs-sss/medi-assur/index-eng.php>

For more information on the *Canada Health Act* visit:

<http://www.hc-sc.gc.ca/hcs-sss/medi-assur/cha-lcs/index-eng.php>

Health Canada

Health Canada is the federal department responsible for helping the people of Canada maintain and improve their health. Health Canada works in partnership with provincial and territorial governments to develop health policy, enforce health regulations, promote disease prevention, and enhance healthy living for all Canadians and is responsible for approving drugs, natural health products and medical devices for use in Canada. For more information about Health Canada visit:

<http://www.hc-sc.gc.ca>

Non-Insured Health Benefits (NIHB) for First Nations and Inuit

The NIHB program through Health Canada offers eligible First Nations and Inuit people with a specified range of medically necessary, health-related goods and services when they are not covered through private insurance plans or provincial/territorial health and social programs. The program includes prescription drugs, over-the-counter medication, medical supplies and equipment, crisis counselling, dental and vision care, and transportation required for medical reasons. For more information on NIHB visit:

<http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/index-eng.php>

Canadian Agency for Drugs and Technologies in Health (CADTH)

CADTH is an independent, not-for-profit agency, funded by Canada's federal, provincial and territorial governments. Its mandate is to deliver timely, evidence-based information to health care leaders on the effectiveness and efficiency of health technologies. For more information on CADTH visit:

<http://www.cadth.ca/>

CADTH's Common Drug Review conducts reviews of the effectiveness of drugs (both clinical and cost), and provides recommendations regarding formulary listing to the publicly funded provincial drug plans in Canada (except Quebec). For more information on the Common Drug Review visit:

<http://www.cadth.ca/index.php/en/cdr>

Clinical Trials

In Canada, clinical trials are regulated and monitored by Health Canada. The process involves a Clinical Trials Application (CTA), required practices that are performed during and after the clinical trial and inspection activities.

To learn more about participating in a clinical trial, view the [Clinical Trials: Information and Options for People with Cystic Fibrosis](#) brochure at www.cysticfibrosis.ca and discuss your eligibility with your CF clinic team.

You can also visit the "[Find a Clinical Trial](#)" section of our Web site for links to searchable databases that allow individuals to access information about active studies currently recruiting in different regions.

Service Canada

Service Canada delivers Government of Canada programs and services, run by various departments, to Canadians. Service Canada offices are located across the country. You can contact the call centres, or find information and forms on the Web site.

<http://www.servicecanada.gc.ca>

Service Canada delivers many programs that are relevant to the CF community. These include:

Canada Pension Plan/Quebec Pension Plan-Disability is designed to provide financial assistance to CPP/QPP contributors who are unable to work because of a severe long-term disability. Benefits are paid monthly to eligible applicants and their dependent children. Certain eligibility criteria must be met in order to receive benefits.

<http://www.servicecanada.gc.ca/eng/isp/pub/cpp/disability/benefits/cppbentoc.shtml>

Employment Insurance Compassionate Care Benefits may be paid to people who have to be away from work temporarily to provide care or support to a family

member who is gravely ill and who has a significant risk of death within 26 weeks (six months). A maximum of six weeks of compassionate care benefits may be paid to eligible people.

http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Child Disability Benefit (CDB) is available to eligible families with low or modest incomes, with children who qualify for the disability amount. The CDB is based on family net income and provides a specific monthly benefit per eligible child to families.

<http://www.servicecanada.gc.ca/eng/goc/cdb.shtml>

Opportunities Fund for Persons with Disabilities provides funding for national, regional and local projects that assist people with disabilities in preparing for and finding employment or self-employment, as well as acquiring the skills necessary to maintain that new employment.

<http://www.servicecanada.gc.ca/eng/of/index.shtml>

Canada Revenue Agency

The Canada Revenue Agency (CRA) administers tax laws for the Government of Canada and most provinces and territories, and various social or economic benefit and incentive programs delivered through the tax system.

To apply for the tax credits, deductions or benefits, an individual must file and complete an income tax form, and the appropriate forms. For more information, refer to the Federal Income Tax Guide or contact the local Canada Revenue Agency (CRA) Tax Services Office.

<http://www.cra-arc.gc.ca>

There are a number of tax credits, deductions and benefits that individuals with cystic fibrosis and their families may be able to claim or receive, including:

Disability Tax Credit (DTC), known as the “disability amount” on your income tax return. Individuals with cystic fibrosis may qualify for the DTC if a medical doctor certifies that they need, and dedicate time for, life-sustaining therapy at least three times a week, for an average of 14 hours a week. Cystic Fibrosis Canada’s [Disability Tax Credit and Cystic Fibrosis](#) brochure is available online, or at your CF clinic or local chapter.

Child Tax Benefit, a tax-free monthly payment made to eligible families to help them with the cost of raising children under age 18.

Child Disability Benefit (CDB), a tax-free benefit for families who care for a child under age 18 who is eligible for the “disability amount”.

Registered Disability Savings Plan (RDSP), a savings plan to provide for the long-term financial security of a beneficiary who has a prolonged physical or mental

impairment. The beneficiary named under an RDSP must be eligible to receive the Disability Tax Credit, and have a valid Social Insurance Number. Cystic Fibrosis Canada's [Registered Disability Savings Plan and Cystic Fibrosis](#) brochure is available online, or at your CF clinic or local chapter.

Medical Expenses Tax Credit, a credit that can be claimed for a person, their spouse or common-law partner, and children. Allowable medical expenses are listed in the CRA's General Income Tax and Benefit Guide, or the Guide to Medical and Disability-Related Information. If medical treatment is not available locally, a person may be able to claim the cost of travelling to get the treatment elsewhere.

Working Income Tax Benefit (WITB), a refundable tax credit intended to provide tax relief for eligible working low income individuals and families who are already in the workforce.

Caregiver Tax Credit may be claimed if a person has maintained a dwelling where s/he and a dependent lived.

Goods and services tax/harmonized sales tax (GST/HST) exemptions are available to qualifying persons with disabilities, and include health care services, personal care and programs, recreational programs, medical devices and supplies.

Family Caregiver Tax Credit, effective January 1, 2012, provides a 15% non-refundable credit for caregivers of infirm dependent relatives. The new tax credit will be claimed as an enhanced amount under one of the following credits: the Spouse or Common-Law Partner Credit, the Child Tax Credit, the Eligible Dependant Credit, the Caregiver Credit or the Infirm Dependant Credit.

More information about programs or credits available to persons with disabilities and their families can be found at:

<http://www.cra-arc.gc.ca/disability/>

Human Rights

In Canada, two pieces of federal legislation ensure personal rights and freedoms, and protection against discrimination:

Charter of Rights: The Charter is the cornerstone of Canada's constitution, and mandates that personal rights and freedoms cannot be encroached upon by legislation or regulations. For more information:

Tel: 819-994-3458
 Toll free: 1-866-811-0055
 E-mail: droits-rights@pch.gc.ca
 Web site: http://www.canadianheritage.gc.ca/progs/pdp-hrp/canada/freedom_e.cfm

Canadian Human Rights Act: The Act grants protection from discrimination to the consumers of federally regulated services, facilities, and accommodation, and to persons employed in businesses operated or regulated by the federal government.

For more information, contact the Canadian Human Rights Commission:

Tel: 613-995-1151
Toll free: 1-888-214-1090
Web site: <http://www.ccdp-chrc.gc.ca>

Most provinces have their own Human Rights Commission which sets guidelines for dealing with discrimination by provincial government departments and their employees. Contact information for each province's Commission can be found under the heading 'Advocacy Resources' of the province's section in *The Guide*.

A provincial Ombudsman is also available to assist you with a complaint against a provincial government or its agencies. The Office of the Ombudsman may, depending on the province, have the power to investigate complaints from the public regarding Provincial Government Ministries, Crown Corporations and Agencies, hospitals, schools and school boards, universities, colleges, professional bodies and local governments. The Ombudsman has the authority to conduct an investigation into any complaint under its jurisdiction and make recommendations with the aim of ensuring that practices and policies are fair.

If you feel that you have been a victim of discrimination on the basis of your physical condition, you may be able to solicit help (peer support, advocacy, or research) from an advocacy or affirmative action centre for the disabled. National organizations are listed below, and provincial/local centres are listed, by province, in *The Guide*.

Advocacy Organizations and Services

The Active Living Alliance for Canadians with a Disability exists to promote, support and enable Canadians with disabilities to lead active, healthy lives. They advocate for individuals with disabilities, provide resources and promote programs and events across the country.

Tel: 613-244-0052
Toll free: 1-800-771-0663
E-mail: ala@ala.ca
Web site: <http://www.ala.ca/>

Reach Canada works to improve the quality of life for individuals with disabilities by offering lawyer referral and educational services at the community level.

Tel: 613-236-6636
Toll free: 1-800-465-8898
E-mail: reach@reach.ca
Web site: <http://www.reach.ca>

March of Dimes Canada provides essential programs and resources across the country to people with physical disabilities.

Tel: 416-425-3463 (head office)
Toll free: 1-800-263-3463

E-mail: info@marchofdimes.ca
 Web site: <http://www.marchofdimes.ca>

The Council of Canadians with Disabilities advocates at the federal level to improve the lives of men and women with disabilities in Canada, by eliminating inequality and discrimination.

Tel: 204-947-0303
 E-mail: ccd@ccdonline.ca
 Web site: <http://www.ccdonline.ca>

Canadian Council on Social Development is a non-profit social policy and research organization focusing on issues such as poverty, social inclusion, disability, cultural diversity, child well-being, employment and housing.

Tel: 613-236-8977
 E-mail: taillon@ccsd.ca
 Web site: <http://www.ccsd.ca>

National Educational Association of Disabled Students advocates for increased accessibility so that disabled students may gain equal access to college or university education.

Tel: 613-380-8065
 Toll free: 1-877-670-1256
 E-mail: info@neads.ca
 Web site: <http://www.neads.ca>

Financial and Social Support Services

Hope Air assists with the cost of air transportation for individuals seeking medical treatment. Qualifying individuals must demonstrate financial need and have a scheduled appointment for recognized medical treatment.

Toll free: 1-877-346-HOPE (4673)
 E-mail: mail@hopeair.org
 Web site: <http://www.hopeair.org>

Starlight Children's Foundation is an international organization working to better the lives of children with serious illness and their families. It provides 'Starlight Sites' within hospitals for children and families to enjoy 'distractive' entertainment and more.

Tel: 514-288-WISH (9474)
 Toll free: 1-888-782-7947
 E-mail: starlight@starlightcanada.ca
 Web site: <http://www.starlightcanada.ca>

Educational Awards - Scholarships and Bursaries

Most post-secondary institutions have on-campus organizations or departments to assist students with disabilities or in financial need. Students with CF should investigate their campus, or potential campus' services. Most application deadlines come-up as early as March, so research early.

There are several provincial scholarships and bursary programs that exist to help students in financial need and/or recognize outstanding achievement in various areas. There are also Web sites that are dedicated to listing awards from all areas for easy searching and access.

Canada Student Grant for Students with Permanent Disabilities is available to individuals with a disability who have demonstrated financial need. It assists in covering the costs of accommodation, tuition, books, and other education-related expenses up to \$2,000 per loan year.

Canada Study Grant for the Accommodation of Students with Permanent Disabilities can provide up to \$8,000 per loan year to help pay for exceptional education-related costs associated with your disability.

These programs are administered through provincial student financial assistance offices. For contact information in your province visit:

<http://www.canlearn.ca/eng/main/help/contact/cao.shtml>

Repayment Assistance Plan for Borrowers with a Permanent Disability (RAP-PD) is available to borrowers with a permanent disability who are having difficulty repaying their student loan debt. RAP-PD makes it easier for borrowers with a permanent disability to manage their student debt by paying back what they can reasonably afford.

Toll free: 1-888-815-4514

Web site: <http://www.canlearn.ca/eng/main/help/contact/csl.shtml>

Disabilityawards.ca is an online tool that helps students with disabilities find financial assistance programs they are eligible for. The site contains information on all disability-based scholarships, awards, and bursaries offered through Canadian colleges and universities, non-governmental and charitable organizations, the private sector, and grant and loan programs available from federal and provincial/territorial governments.

KIN Canada Bursaries provides financial assistance to those seeking higher education. Applicants to the Kin Canada Bursaries must be Canadian citizens or permanent residents, and must plan to be studying at a post-secondary institution the following year.

Tel: 519-653-1920 ext. 215

Toll free: 1-800-PICK KIN ext. 215

E-mail: bzak@kincanada.ca

Web site: <http://www.bursary.ca>

Other Services and Resources

WORKink is Canada's largest virtual employment resource centre for job seekers with disabilities.

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

Canada Benefits is a Government of Canada Web site that connects individuals to provincial and federal government benefits (including tax benefits, scholarships, bursaries and more).

<http://www.canadabenefits.gc.ca>

[DrugCoverage.ca](http://www.drugcoverage.ca) is a Web site that provides information on the various types of private drug insurance plans, provincial/territorial drug benefit programs, and federal drug plans available in Canada. It also provides links to government sites.

Alberta

Clinics

Alberta Children's Hospital (paed.)*

2888 Shagnappi Trail NW

Calgary, Alberta T3B 6A8

Director: Dr. C. Bjornson

Nurse Coordinator: Lori Fairservice

Clinic 403-955-7319

Emergency 403-955-7211

Office 403-955-2952

Fax 403-955-7527

University of Calgary Medical Clinic (adult)

Health Sciences Centre, 3330 Hospital Drive NW

Calgary, Alberta T2N 4N1

Director: Dr. H.R. Rabin

Clinic Administrator: Valerie Levesque

Clinic 403-220-5951

Emergency 403-944-1110

Office 403-220-5951

Fax 403-270-2772

University of Alberta Hospitals (paed.)

4-590 Edmonton Clinic Health Academy

11405 - 87 Avenue

Edmonton, Alberta T6G 2B7

Director: Dr. P. Zuberbuhler

Nurse Coordinator: Angela MacDonald

Clinic 780-248-5580

Emergency 780-248-8432

Fax 780-248-5627

University of Alberta Hospitals (adult)

7-109 Clinic Science Building

8440 - 112 Street

Edmonton, Alberta T6G 1C9

Director: Dr. N. Brown

Nurse Coordinator: Joan Tabak

Clinic 780-407-6745

Emergency 780-407-8822

Fax 780-407-3112

Outreach Clinic

*An outreach clinic is held in Medicine Hat, AB, twice yearly.

Clinic Resources

Health Professional	Alberta Children's Hospital (paed.)	University of Calgary Medical Clinic (adult)	University of Alberta Hospitals (paed./adult)
Physiotherapist	YES	YES	YES
Social Worker	YES	YES	YES
Dietitian	YES	YES	YES
Respirologist/Pulmonologist	YES	YES	YES
Gastroenterologist	YES	*	*
Psychologist/Psychiatrist	YES	YES	*
Pharmacist	YES	YES	*
Endocrinologist	*	*	*

*on referral

Hospital Facilities

Service	Alberta Children's Hospital (paed.)	University of Calgary Medical Clinic (adult)	University of Alberta Hospitals (paed./adult)
Rooming in	YES	N/A	YES
Care by parent	NO	N/A	YES
Hostel service	YES*	YES	YES
Educational program - e.g. Tutor	YES**	NO	YES
Recreational activities - e.g. Play program	YES	NO	YES
Teen Unit	YES	NO	YES***
Adult Unit	NO	YES	YES

*[Ronald McDonald House](#) **Yes, to Tutor only *** Special teen room

Patients who are positive for *Burkholderia cepacia* complex are given private rooms, and use separate physiotherapy equipment.

Drug Plan

For individuals with CF under 18 years of age, the provincial CF Drug Program covers antibiotics and enzymes. For other medications, vitamins and nutritional supplements, and for individuals over the age of 18, obtaining private insurance is encouraged. Pulmozyme® is provided to individuals with CF under Province-wide Services.

An option for those without supplementary coverage is the [Non-Group Prescription Drug Coverage](#), offered through Alberta Blue Cross. Under this plan, premiums are paid on a quarterly basis (single or family rate) and there is a co-payment of 30 per cent of the cost, to a maximum of \$25, for each drug prescribed. If a more expensive brand name drug is chosen instead of an equivalent generic drug, the additional cost must be paid.

Alberta Human Resources and Employment contracts with Alberta Blue Cross to offer health benefits, including prescription drugs for the following client groups:

- [Income Support](#), for Albertans who don't have the resources to meet their basic needs.
- [Alberta Adult Health Benefit](#), for Albertans who leave income support.
- [Assured Income for the Severely Handicapped](#) (AISH), for adults who have a permanent disability which severely affects their ability to earn a livelihood.
- [Alberta Child Health Benefit](#), for children of low-income families.

For general inquiries related to the Alberta Health Care Insurance Plan contact:

Tel: 780-427-1432
 Toll free: 310-0000, then 780-427-1432
 E-mail: health.ahcipmail@gov.ab.ca

For more information on **Alberta Health and Wellness Prescription Drug Programs**, and for links to the various programs listed above visit:

<http://www.health.alberta.ca/AHCIP/prescription-program.html>

Nutritional Supplements

For children and adults with CF requiring enteral feeding, financial assistance may be provided through the [Home Enteral Nutrition Program \(Southern Alberta\)](#) or [Northern Home Nutrition Support Program](#) on referral through a CF physician. Monthly fees may be required. For more information contact the local CF clinic.

Home Enteral Nutrition Program (Southern Alberta)

<http://www.albertahealthservices.ca/services.asp?pid=service&rid=1943>

Northern Home Nutrition Support Program

<http://www.albertahealthservices.ca/services.asp?pid=service&rid=7366>

Equipment and Oxygen

Some equipment, including oxygen may be available through the **Alberta Aids to Daily Living (AADL) Program** for little or no cost. For more information contact:

Tel: 780-427-0731
 Toll free: 310-0000, then 780-427-0731
 Web site: <http://www.seniors.gov.ab.ca/aadl/>

Homecare

Medically prescribed home nursing care and physiotherapy are provided under the Alberta Health Care Insurance Plan. Homemaker services are also available. In cases of hardship, financial assistance may be provided through provincial social services programs. Contact the clinic coordinator (Edmonton) or the clinic social worker (Calgary) for details.

Genetic Counselling

Genetic counselling and testing is available at no charge to residents of Alberta on referral through a CF physician. Testing is available in Alberta at the following laboratories:

<p>University of Alberta Medical Genetics Clinic 853 Medical Sciences Building Edmonton, Alberta T6G 2B7 Tel: 780-407-7333</p>	<p>Alberta Children's Hospital Medical Genetics 2888 Shaganappi Trail NW Calgary, Alberta T3B 6A8 Tel: 413-955-7373</p>
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Newborn Screening

Alberta screens newborns for cystic fibrosis. Please refer to Cystic Fibrosis Canada's [Newborn Screening for Cystic Fibrosis](#) brochure for further information.

Social Support

Contact the local [Cystic Fibrosis Canada chapter](#) or [CF clinic](#) for details of the existing social support network in the area. There are chapters in Calgary ([Calgary and Southern Alberta](#)), Red Deer ([Central Alberta](#)), and Edmonton ([Edmonton and Northern Alberta](#)). Please see the back of this [Guide](#) for a listing of all chapters across Canada.

Family Support for Children with Disabilities (FSCD) program provides a range of support and services for children with disabilities and their families. It is a provincial program that is delivered regionally.

<http://www.child.alberta.ca/home/591.cfm>

Starlight Children's Foundation (Calgary Regional Office) provides services for seriously ill children and their families. The Starlight Foundation runs online programs including *Starbright World*, an online networking service for teens and the *Great Escapes* program for families, in the Calgary and Edmonton areas.

Tel: 403-457-0344
 Fax: 403-457-0384
 E-mail: laura.stow@starlightcanada.org
 Web sites: www.starlightcanada.org
www.starbrightworld.org

Educational and Vocational Counselling

Alberta Learning Information Service (ALIS) provides information for career planning, post-secondary education and training, educational funding, job search, labour market trends, and workplace issues. ALIS also provides information on resources and services for people with disabilities.

Student Funding

Tel: 780-427-3722
Toll free: 1-800-222-6485

Career Planning, Work Search and Educational Options

Tel: 780-422-4266
Toll free: 1-800-661-3753
Web site: <http://alis.alberta.ca/>

Entrepreneurs with Disabilities program provides western Canadians with disabilities with easy access to business information, training and development, mentoring and one-on-one counselling services, and financing in their pursuit of self-employment and entrepreneurship. The program is administered by the federal department Western Economic Diversification Canada, and is delivered through regional offices across western Canada.

<http://www.wd.gc.ca/eng/273.asp>

Financial Assistance

Alberta Works helps unemployed people find and keep jobs and help Albertans with low incomes cover their basic costs of living. The program offers services including [Income Support](#), [Health Benefits](#) and [Financial Support for Training](#).

<http://employment.alberta.ca/FCH/3171.html>

Assured Income for the Severely Handicapped (AISH) program provides financial and health-related assistance to eligible adults with a disability. The disability must be permanent and substantially limit the person's ability to earn a living.

<http://www.seniors.alberta.ca/aish/>

For information on Alberta Works or Assured Income for the Severely Handicapped, contact:

Alberta Supports Contact Centre

Tel: 780-644-9992 (in Edmonton)
Toll free: 1-877-644-9992
E-mail: iscc@gov.ab.ca

Variety - The Children's Charity Alberta has programs to assist children with special needs who require financial assistance. To apply, the recipient must be under 19 years of age and have a disability. Variety will not consider requests for services covered by any other provincial program. Contact Variety Alberta or your social worker for more information.

Tel: 403-228-6168
Web site: <http://www.varietyalberta.ca/>

Advocacy Resources

Cystic Fibrosis Canada is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Canada.

Alberta Civil Liberties Research Centre provides information, teaching and materials, and conducts research on civil liberties and human right issues concerning Albertans. The Research Centre does not engage in advocacy, but is a good informational resource.

Tel: 403-220-2505
 Fax: 403-284-0945
 E-mail: aclrc@ucalgary.ca
 Web site: <http://www.aclrc.com>

Alberta Human Rights and Citizenship Commission is an independent commission of the Government of Alberta that works to foster equality and reduce discrimination through public education initiatives and the resolution and settlement of complaints of discrimination. The Commission also provides resources and contact information for other organizations with similar goals.

Tel: 780-427-7661 (Northern Alberta)
 403-297-6571 (Southern Alberta)
 E-mail: humanrights@gov.ab.ca
 Web site: <http://www.albertahumanrights.ab.ca>

Alberta Committee for Citizens with Disabilities (ACCD) is a consumer-directed organization that actively promotes full participation in society for Albertans with disabilities; it does this through public education, research and policy analysis, funding (including scholarships and bursaries) and more.

Tel: 780-488-9088
 Toll free: 1-800-387-2514
 E-mail: accd@accd.net
 Web site: <http://www.accd.net/>

Alberta Disabilities Forum (ADF) is a coalition of 43 not-for-profit provincial disability organizations whose members speak with a unified voice on cross-disability issues of concern for Albertans with disabilities.

Tel: 780-488-9088
 E-mail: adf@accd.net
 Web site: <http://www.adforum.ca>

The Premiers Council on the Status of Persons with Disabilities makes recommendations to the Government of Alberta on matters relating to the opportunity for full and equal participation of persons with disabilities within the province. It aims to improve the lives of persons with disabilities by listening to issues of the disability community and communicating these issues to government.

Tel: 780-422-1095
 Toll free: 1-800-272-8841
 E-mail: pcspd@gov.ab.ca
 Web site: <http://www.seniors.gov.ab.ca/premierscouncil>

British Columbia

Clinics

BC Children’s Hospital (paed.)*

Room K3-189 Ambulatory Care Building
4480 Oak Street
Vancouver, British Columbia V6H 3V4
Director: Dr. M. Chilvers
Nurse Coordinator: Anna Gravelle

Clinic	604-875-2345 x 7005
Emergency	604-875-2134
Main	888-300-3088
Office	604-875-2146
Fax	604-875-2349

St. Paul’s Hospital (adult)**

1081 Burrard Street
Vancouver, British Columbia V6Z 1Y6
Director: Dr. P. Wilcox
Nurse Coordinator: Catherine MacDonell

Clinic	604-682-2344 x 63892
Main	604-682-2344
Office	604-806-8522
Fax	604-806-8122

Victoria General Hospital (paed.)

#1 Hospital Way
Victoria, British Columbia V8Z 6R5
Director: Dr. S. Kent
Nurse Coordinator: June Jacob

Clinic	250-727-4450
Emergency	250-727-4212
Office	250-727-2156
Fax	250-727-4211

Royal Jubilee Hospital (adult)

8 North, Patient Care Centre
1952 Bay Street
Victoria, British Columbia V8R 1J8
Director: Dr. I. Waters
Nurse Coordinator: Sharon Wiltse

Clinic	778-679-2521
Office	250-592-1354
Fax (Waters)	250-592-9291
Fax (Clinic)	250-519-1682

All four CF clinics have policies in place to segregate CF patients colonized with *Burkholderia cepacia* complex and other antibiotic resistant organisms.

Outreach Clinics

*Outreach clinics are held twice yearly in Kamloops and Prince George. For further information on the CF clinic at BC Children’s, visit: <http://www.bcchildrens.ca> and click on “services” - “specialized paediatrics” - “cystic fibrosis clinic”.

**An adult outreach clinic is held twice yearly in Kamloops, B.C.

Clinic Resources

Health Professional	BC Children's Hospital (paed.)	St. Paul's Hospital (adult)	Victoria Gen. Hosp. (paed.)	Royal Jubilee Hosp. (adult)
Physiotherapist	YES	YES	YES	YES
Social Worker	YES	YES	YES	YES
Dietitian	YES	YES	YES	YES
Respirologist/Pulmonologist	*	YES	YES	YES
Gastroenterologist	YES	*	*	*
Psychologist/Psychiatrist	*	YES	YES	*
Pharmacist	*	*	YES	YES
Endocrinologist	*	*	*	*

*on referral

Hospital Facilities

Service	BC Children's Hospital (paed.)	St. Paul's Hospital (adult)	Victoria Gen. Hosp. (paed.)	Royal Jubilee Hosp. (adult)
Rooming in	YES	N/A	YES	N/A
Care by parent	NO	N/A	NO	N/A
Hostel service (Easter Seal House and Heather House)	YES	NO	NO	NO
Educational program - e.g. Tutor	YES	NO	YES	NO
Recreational activities - e.g. Play program	YES	NO	YES	NO
Teen Unit	NO	NO	NO	NO
Adult Unit	NO	YES	NO	YES

At St. Paul's Hospital patients who are not colonized with *B. cepacia* complex are segregated, by ward, from patients colonized with *B. cepacia* complex.

At BC Children's Hospital, all admitted patients will have their own room. Any patient who is colonized with *B. cepacia* complex is admitted to a ward with no other CF patients on it.

At the Royal Jubilee Hospital, all admitted patients will have their own room and a private bathroom.

Drug Plan

Health Insurance BC administers the [Medical Services Plan \(MSP\)](#) and Pharmacare programs to assist BC residents with medical services and procedures, prescription drugs, and designated medical supplies. The PharmaCare program subsidizes eligible prescription drugs and designated medical supplies for all qualified residents, and provides financial assistance under Fair Pharmacare and other specialty plans for individuals with exceedingly high drug costs relative to their annual income.

Health Insurance BC

http://www.health.gov.bc.ca/insurance/about_hi.html

PharmaCare

<http://www.health.gov.bc.ca/pharmacare/>

Fair PharmaCare

<http://www.health.gov.bc.ca/pharmacare/plani/planiindex.html>

Fair PharmaCare is based on net (family) income for the previous two years, and determines a deductible (the amount at which PharmaCare begins paying at least 70% of medication costs), and a ceiling (the maximum amount that a family or individual will pay for all eligible medications in a single year). To be eligible for PharmaCare, an individual must: be a resident of British Columbia for at least three (consecutive) months; be registered with the Medical Services Plan (MSP); be a resident of Canada for the last 12 months; be either a Canadian citizen or holder of permanent resident status (individuals here on student visas may be eligible for PharmaCare coverage if certain other criteria are met); and have filed a recent tax return (within the past two years). To register for Fair PharmaCare contact:

Tel: 604-683-7151
 Toll free: 1-800-663-7100
 Web site: <https://pharmacare.moh.hnet.bc.ca/>

Other specialty plans:

Plan C -Income Assistance

Recipients of BC Income Assistance are eligible for *Plan C*, which provides 100% coverage of eligible prescription costs for BC residents receiving medical benefits and income assistance through the Ministry of Housing and Social Development.

Plan D - Cystic Fibrosis

Individuals with cystic fibrosis who are registered with a provincial clinic receive coverage of digestive enzymes and other products listed in the [Cystic Fibrosis Formulary](#). To obtain CF medications through *Plan D*, individuals must have their diagnosis confirmed at a CF clinic, be registered for the plan, attend a CF clinic in BC at specified intervals, and have prescriptions written by a CF clinic physician.

Please note: Coverage for other products in the CF formulary, under *Plan D*, is subject to the rules of a patient's primary plan: *Plan C* (Income Assistance), *Plan F* (At-Home Program) or Fair PharmaCare.

Plan F - At-Home Program

This program provides community-based, family-style care for severely handicapped children who would otherwise become reliant on institutional care. Children receiving full benefits or medical benefits through the program qualify for full coverage of eligible prescription drugs and designated medical supplies.

Special Authority

Some medications that are not covered under PharmaCare and are not listed in the formulary may be available through a process called [Special Authority](#). To receive consideration for this coverage, a CF physician must justify the need through an application to PharmaCare. Each application is assessed on a case-by-case basis. Contact the CF clinic coordinator or physician for more information.

Equipment and Oxygen

Individuals are responsible for procuring their own equipment. Extended health benefit plans may cover some or all of the costs of some equipment. Oxygen may be covered under the BC medical plan and/or extended health benefit plans. Contact the CF clinic coordinator or social worker for more information.

Homecare

In-home services are available for eligible individuals in BC, and may include (but are not limited to): home care nursing, rehabilitation and some physiotherapy, home support, home IV, and oxygen therapy. Community-based services are also available and include: adult day programs; meal programs; assisted living; residential care services and hospice care. Case management services are provided in both the home and community. Contact your CF clinic for more information.

Genetic Counselling

Genetic counselling and testing are available on referral through a family physician or CF clinic physicians. There is no cost to individuals for this service. The laboratory in British Columbia, which performs genetic testing for CF, is:

University of British Columbia

Department of Medical Genetics
4500 Oak Street, Room C234
Vancouver, British Columbia V6H 3N1
Tel: 604-875-2157

Newborn Screening

British Columbia screens newborns for cystic fibrosis. Please refer to Cystic Fibrosis Canada's [Newborn Screening for Cystic Fibrosis](#) brochure for further information.

Social Support

Contact the local [Cystic Fibrosis Canada chapter](#) or [CF clinic](#) for details on the existing social support network in the area. In Vancouver and Interior B.C., Cystic Fibrosis Canada chapters are located in [Kamloops](#), [Okanagan Valley](#), [Prince George](#) and [Vancouver](#). On Vancouver Island, chapters are located in [Campbell River](#), [Nanaimo](#), [Victoria](#) and [Powell River](#). Please see the back of this [Guide](#) for a listing of all chapters across Canada.

Educational and Vocational Counselling

Vocational counselling is available to young people through their high schools. For Vocational Rehabilitation Services contact the CF clinic social worker or school counsellor. Depending on the financial situation of the CF individual and family, there is a possibility of assistance with tuition, books, and room and board for students planning to attend a post-secondary institution.

Employment Program for Persons with Disabilities (EPPD) provides a range of specialized services to help individuals with disabilities by providing individualized services including career planning and assessment, job related skills training, and self-employment services. For more information visit:

<http://www.hsd.gov.bc.ca/pwd/eppd.htm>

Financial Assistance

CF Travel & Medication Government Grant assists individuals with CF and their families with the costs of CF-related prescribed medications, and travel for visits to CF clinics and CF-related hospitalizations. To qualify, individuals must register with Fair PharmaCare and submit a Grant Reimbursement Application Form with their first claim, and whenever their circumstances change. Reimbursement is in accordance with the BC CF Association policies and subject to the limitations of the grants. Contact your CF clinic for more information.

Travel Assistance Program (TAP) helps alleviate some of the transportation costs for eligible BC residents who must travel within the province for medical services not available in their own community. TAP is a partnership between the Ministry of Health Services and private transportation carriers, who discount or waive their regular fees. TAP does not provide direct financial assistance to patients for travel costs, and does not include accommodation, fuel or local transportation expenses.

Tel: 250-952-1742
 Toll free: 1-800-465-4911
 E-mail: HLTH.RuralHealth@gov.bc.ca
 Web site: <http://www.health.gov.bc.ca/tapbc>

BC Family Residency Program provides accommodation assistance to enable families to stay together when their child requires medical care at BC Children's Hospital. Enhanced travel assistance is also provided through ground transportation for children and air transportation for patients of all ages. Any family with permanent residency in BC and Medical Services Plan coverage is eligible for assistance. Families must receive confirmation of eligibility from a medical or community service professional and reside outside the Metro Vancouver area. For more information contact:

Tel: 1-800-465-4911
 Web site: <http://www.bcfamilyresidence.gov.bc.ca>

Health Connections offers subsidized transportation options to help defray costs for rural residents who must travel to receive medical care outside their home communities.

http://www.busonline.ca/health_connections/

Medical Travel Accommodations Listing, provides a list of businesses who offer accommodation at discounted rates to patients and their families who must travel for medical treatment. To book at the reduced rate, individuals should contact the hotel they wish to stay at, request the medical rate when booking, and be prepared to provide documentation such as a doctor's note.

<http://www.pss.gov.bc.ca/csa/categories/accommodation/medical/search/>

Premium Assistance for Medical Service Plan is available through the Ministry of Health, on the basis of financial need. For more information, visit:

<http://www.health.gov.bc.ca/msp/infoben/premium.html>

Ministry of Housing and Social Development has a variety of programs to assist individuals with disabilities or financial hardship to maintain a certain level of income security. Assistance may be provided if a person is: out of work or earning very little; unable to work; or, working and in need of child care. Eligibility and monthly assistance rates depend on income and asset levels, and the number of people in the family unit. Hardship assistance may be issued in some situations when an individual is not eligible for income assistance. For more information contact:

Tel: 1-866-866-0800

Web site: http://www.hsd.gov.bc.ca/disability_strategy.htm

WorkAble Solutions connects individuals with disabilities to employers, and provides resources.

<https://www.workablesolutionsbc.ca/>

Entrepreneurs with Disabilities provides western Canadians with disabilities access to business information, training and development, mentoring and one-on-one counselling services, and financing in their pursuit of self-employment and entrepreneurship. For more information, visit:

<http://www.wd.gc.ca/eng/273.asp>

BC Housing provides subsidized housing options for residents of British Columbia. This includes the Rental Assistance Program which pays a portion of the monthly rent for low income working families.

Tel: 604-433-2218

Toll free: 1-800-257-7756

Web site: <http://www.bchousing.org>

Starlight Children's Foundation (British Columbia Regional Office) provides services for seriously ill children and their families. The Starlight Foundation runs online programs including *Starbright World*, an online networking service for teens and the *Great Escapes* program for families, in the Vancouver and Victoria areas.

Tel: 604-742-0272

Fax: 604-742-0274

E-mail: heather@starlightcanada.org
Debbie@starlightcanada.org (*Great Escapes*)

Web sites: www.starlightcanada.org
www.starbrightworld.org

Variety - The Children's Charity of BC has programs to assist children with special needs who require financial assistance. Recipients must be under 19 years of age and have a disability. Variety will not consider requests for services covered by any other provincial program.

Tel: 604-268-3893
Toll free: 1-800-381-2040
E-mail: heart.fund@variety.bc.ca

Advocacy Resources

Cystic Fibrosis Canada is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Canada.

British Columbia Coalition of the People with Disabilities represents people with all types of disabilities throughout BC. It supports people with disabilities through direct services, community partnerships, advocacy, research and publications.

Tel: 604-875-0188
Toll free: 1-800-663-1278
Fax: 604-875-9227
E-mail: feedback@bccpd.bc.ca
Web site: <http://www.bccpd.bc.ca>

The British Columbia Public Interest Advocacy Centre works to advance the interests of groups that are generally unrepresented or underrepresented in issues of major public concern. This includes advocating on issues of disability rights, human rights and welfare rights.

Tel: 604-687-3063
Fax: 604-682-7896
E-mail: bcpiac@bcpiac.com
Web site: <http://www.bcpiac.com>

BC211 is a telephone service which connects people to community, social and government agencies and services across BC's lower mainland. There is also an online directory, called the Red Book, listing advocacy groups, non-profit agencies, hospitals, health clinics, and more.

Tel: 211 or 604-875-6431
E-mail: info@bc211.ca
Web sites: <http://www.bc211.ca/>
<http://redbookonline.bc211.ca/> (Red Book)

Manitoba

Clinics

Children's Hospital of Winnipeg (paed.)

840 Sherbrook Street - Room CS 518

Winnipeg, Manitoba R3A 1S1

Director: Dr. H. Pasterkamp

Nurse Coordinator: Jane Mayo

Clinic	204-787-8834
After-hours	204-787-2071
Office	204-787-1944
Fax	204-787-1944
Nurse	204-787-2079

Health Sciences Centre (adult)

820 Sherbrook Street - RS-114

Winnipeg, Manitoba R3A 1R8

Director: Dr. W. Kepron

Nurse Coordinator: Patricia Haines

Clinic	204-787-1472
Main	204-787-3661
Office	204-787-2338
Fax	204-787-2420

Clinic Resources

Health Professional	Children's Hospital of Winnipeg (paed.)	Health Sciences Centre (adult)
Physiotherapist	YES	YES
Social Worker	YES	YES
Dietitian	YES	YES
Respirologist/Pulmonologist	YES	YES
Gastroenterologist	*	YES
Psychologist/Psychiatrist	*	*
Pharmacist	YES	*
Endocrinologist	*	*

*on referral

The Children's Hospital has a child life therapist, teacher, spiritual and mental health nurse, and homecare nurse.

Hospital Facilities

Service	Children's Hospital of Winnipeg (paed.)	Health Sciences Centre (adult)
Rooming in	YES	N/A
Care by parent	NO	N/A
Hostel service	*	YES
Educational program - e.g. Tutor	YES	NO
Recreational activities - e.g. Play program	YES	NO
Teen Unit	YES	NO
Adult Unit	N/A	YES

*[Ronald McDonald House](#) and [Lennox Bell Lodge](#)

Patients with CF are not admitted to the same room at either hospital.

Drug Plan

[Manitoba Pharmacare](#) is a drug benefit program for any Manitoban, regardless of age, whose income is seriously affected by high prescription drug costs. Pharmacare coverage is based on both your total family income and the amount you pay for eligible prescription drugs. Each year you are required to pay a portion of the cost of your eligible prescription drugs. This amount will be your annual Pharmacare deductible, and is based on annual family income. Once the deductible has been reached, the Pharmacare program will pay for 100% of eligible medications for the remainder of the benefits year.

To be eligible for the Pharmacare program, an individual must be eligible for Manitoba Health coverage, not have prescriptions covered through other provincial or federal programs, and not have prescriptions covered by a private drug insurance program. Some common drugs for individuals with CF are not listed on the [Manitoba Formulary](#), but they may be obtained and approved for coverage under the [Exception Drug Status Program](#).

Manitoba Health Provincial Drug Program

Tel: 204-786-7141
 Toll free: 1-800-297-8099
 E-mail: pharmacare@gov.mb.ca
 Web site: <http://www.gov.mb.ca/health>

Equipment and Oxygen

Equipment such as percussors, compressors, nebulizers, postural drainage boards, humidifiers, suction machines, home oxygen equipment and enteral feeding supplies are available to individuals with CF if they qualify through their Regional Health Authority. For information and servicing, contact the CF nurse coordinator.

Homecare

Nursing, physiotherapy, home IV, home oxygen, homemaker services, assistance with daily living, enteral supplies and temporary respite for families of individuals with CF are available in most areas of the province. Services are provided without charge (for those that qualify) by the [Manitoba Ministry of Health's Home Care Program](#).

<http://www.gov.mb.ca/health/homecare>

Genetic Counselling

Genetic counselling and testing are available to residents of Manitoba on referral through a CF physician. There is no charge for these services as Manitoba Health covers it. The laboratory in Manitoba, which performs genetic testing for CF, is:

Health Sciences Centre
Molecular Diagnostic Laboratory
820 Sherbrook Street
Winnipeg, Manitoba R3A 1R9
Tel: 204-787-2843
Lab: 204-787-1534

Newborn Screening

Manitoba screens newborns for cystic fibrosis. Please refer to Cystic Fibrosis Canada's [Newborn Screening for Cystic Fibrosis](#) brochure for further information.

Social Support

Contact the [Cystic Fibrosis Canada Winnipeg Chapter](#) or [CF clinic](#) for details on the existing social support network in the area. Please see the back of this [Guide](#) for a listing of all chapters across Canada.

Educational and Vocational Counselling

Employment Manitoba offers services to assist individuals in finding jobs, and in keeping employment.

<http://www.gov.mb.ca/employment/>

Manitoba Family Services and Consumer Affairs offers a Vocational Rehabilitation Program to individuals with disabilities. In addition, Public Administration Internship Program for Persons with Disabilities is a two-year training program to provide better opportunities for persons with disabilities to work in government.

http://www.gov.mb.ca/fs/pwd/voc_rehab

Manitoba WorkinfoNET Inc. (MBWIN) provides Manitobans with local employment information, career planning, and training programs. MBWIN connects users to a variety of free, reliable and up-to-date resources in Manitoba in the areas of employment, career planning, and learning.

Tel: 204-231-5543
Fax: 204-831-8467
Web site: <http://mb.workinfont.ca>

A.I.M. for Work helps individuals with physical disabilities or chronic illness find work. The program provides individual services, and also publishes a newsletter with advice and job posting information.

A.I.M. for Work - Selkirk Location

Tel: 204-482-2130
Toll free: 1-800-494-4179
Fax: 204-482-9855
E-mail: aimforwork@mts.net
Web site: <http://www.aimforwork.com>

Steinbach Location

Tel: 204-346-6740
Fax: 204-346-6741
E-mail: rsmcdonald@mts.net

Society for Manitobans with Disabilities (SMD) provides services for the development of independence and community support for persons with disabilities. Vocational counselling is available, and under certain criteria, SMD provides financial assistance for post-secondary education.

Tel: 204-975-3010
Toll free: 866-282-8041
E-mail: info@smd.mb.ca
Web site: <http://www.smd.mb.ca/>

Reaching E-quality Employment Services promotes, facilitates and maintains the employment of persons with disabilities or health conditions by providing diverse and customized employment, training and consultation services.

Tel: 204-832-REES (7337)
Toll free: 1-800-855-0511 (Manitoba Relay Service) then ask for 947-3480
E-mail: info@re-es.org
Web site: <http://www.re-es.org>

Financial Assistance

Manitoba Family Services and Consumer Affairs helps citizens in need to achieve greater self-sufficiency and to participate more fully in society. Individuals with a disability may qualify for the Employment and Income Support Services, which provides income support, health benefits, and subsidies for many services.

Tel: 204-945-5870
E-mail: dpeia@gov.mb.ca
Web sites: <http://www.gov.mb.ca/fs/about/org/spd/programs.html>
<http://www.gov.mb.ca/fs/pwd/iapd.html>

Entrepreneurs with Disabilities Program provides western Canadians with disabilities with easy access to business information, training and development, mentoring and one-on-one counselling services, and financing in their pursuit of self-employment and entrepreneurship.

<http://www.wd.gc.ca/eng/273.asp>

Lions Foundation of Manitoba and Northwestern Ontario provides assistance to individuals in need. There is also an apartment in Winnipeg available to individuals who must travel to receive treatments or attend medical appointments.

Tel: 204-788-8508
 Toll free: 1-800-552-6820
 Fax: 204-943-6823
 E-mail: lsmnoi@mts.net
 Web site: <http://www.eyebankmanitoba.com>

Advocacy Resources

Cystic Fibrosis Canada is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Canada.

Manitoba Human Rights Commission deals with any issues and human right violations which fall under provincial jurisdiction. The Commission mediates and investigates complaints of discrimination, refers matters to adjudication, educates the public, and promotes human rights.

Tel: 204-945-3007 (Winnipeg)
 204-726-6261 (Brandon)
 204-627-8270 (The Pas)
 Toll free: 1-888-884-8681
 E-mail: hrc@gov.mb.ca
 Web site: <http://www.manitoba.ca/hrc>

Manitoba League of Persons with Disabilities (MLPD) represents the concerns of people with all types of disabilities in Manitoba. The organization runs support programs, does policy research, provides information and referral services, and deals with issues, including education and employment.

Tel: 204-943-6099
 Toll free: 1-888-330-1932
 Fax: 204-943-6654
 E-mail : mlpd@shawcable.com
 Web site: <http://www.mlpd.mb.ca>

New Brunswick

Clinic

Horizon Health Network (paed./adult)

Saint John Regional Hospital

P.O. Box 2100

Saint John, New Brunswick E2L 4L2

Directors: Dr. W. Alexander (paed.)

Dr. G. Bishop (adult)

Nurse Coordinator: Rita Stackhouse

Clinic 506-648-6793

Clinic (Nurse) 506-648-6057

Emergency 506-648-6000

Office 506-648-6811

Fax 506-648-6790

Outreach Clinics

The IWK Health Centre in Halifax, Nova Scotia, conducts outreach clinics twice yearly in Bathurst and Fredericton (paediatric only).

Clinic Resources

Health Professional	Saint John Regional Hospital
Physiotherapist	YES
Social Worker	YES
Dietitian	YES
Respirologist/Pulmonologist	YES
Gastroenterologist	*
Psychologist/Psychiatrist	YES (paed.)
Pharmacist	*
Endocrinologist	*

*on referral

Hospital Facilities

Service	Saint John Regional Hospital
Rooming in	YES
Care by parent	NO
Hostel service	NO
Educational program - e.g. Tutor	YES
Recreational activities - e.g. Play program	YES
Teen Unit	YES
Adult Unit	NO

Adult patients colonized with *Burkholderia cepacia* complex are isolated on the adult floor in the hospital, and attend separate clinics.

Drug Plan

Plan B - Cystic Fibrosis Beneficiary Group

New Brunswick Prescription Drug Program (NBPDP) is available to individuals who are diagnosed with CF, registered with New Brunswick Medicare, and who are not entitled to receive similar services from any other source (such as private health insurance). If the private insurer does not cover the cost of CF medications, either some or all, then coverage under *Plan B* may be allowed. A letter stating this along with registration under the NBPDP is required.

If eligible, there is a yearly fee of \$50 and individuals are required to co-pay 20% of the cost of each prescription up to a maximum of \$20. The maximum in co-payment charges is \$500 per family unit per year. Individuals who hold a valid health card (*Plan F*) for prescription drugs, through the Department of Social Development, do not have to pay the yearly registration fee and will have a co-pay to reflect their respective plan.

The drugs and products must be listed on the provincial formulary in order to be considered eligible benefits. However, *Special Authorization* may be granted, in certain circumstances, to allow beneficiaries to obtain drug products not offered as benefits under the NBPDP.

Organ transplant recipients qualify for a separate program under the NBPDP, *Plan R*. The same qualifications as noted for *Plan B* apply to this program.

Prescription Drug Program - Department of Health

Tel: 506-867-4515

E-mail: info@nbpdp-pmonb.ca

Web site: <http://www.gnb.ca/0051/index-e.asp>

Equipment and Oxygen

The provincial government does not pay for equipment such as percussors, compressors, nebulizers, etc. However, if a CF physician prescribes the equipment, some private insurance plans may help to cover the equipment costs. In cases of financial need, assistance for purchasing equipment may be available through the New Brunswick Department of Social Development. Contact your CF clinic for more information.

Oxygen is available through the [Department of Social Development's Health Services Oxygen and Breathing Aids Program](#) to individuals who receive assistance through the Department of Social Development. This program assists with coverage of respiratory equipment and supplies not covered by NB Medicare or private health insurance. It covers: concentrators; tanks/cylinder and refills; oxygen saturation monitors; and other related supplies. Individuals over 65 years of age are not eligible for this program.

Department of Social Development

Tel: 506-453-2001

E-mail: sd-ds@gnb.ca

Web site: www.gnb.ca/socialdevelopment

Homecare

Home IV therapy is provided by **New Brunswick Extra-Mural Program**. Admissions to Saint John Regional Day Hospital are available, when required, for specialized IV medications. Medically prescribed nursing and physiotherapy care are provided without charge by the provincial Department of Health. Homemaker services are charged at prevailing rates. In cases of financial need, assistance is available through the New Brunswick Department of Social Development. The CF nurse coordinator may also be available for home visits when required. Contact your CF clinic for more information.

Genetic Counselling

Genetic counselling is available on referral through a CF physician. Genetic testing is not available in New Brunswick, however, there is a facility at the Atlantic Research Centre in Halifax that services all of the Maritime Provinces. This service is covered by the provincial health plan.

Social Support

Contact your local [Cystic Fibrosis Canada chapter](#) or [CF clinic](#) for details on any existing social support networks in the area. In New Brunswick, Cystic Fibrosis Canada chapters are located in [Fredericton](#), [Moncton](#) and [Saint John](#). Please see the back of this [Guide](#) for a listing of all chapters across Canada.

Educational and Vocational Counselling

Employment counselling is available through the provincial Department of Social Development - Career Development Opportunities for Persons with Disabilities. As well, opportunities may be available through the Department of Post-Secondary Education, Training and Labour.

Department of Post-Secondary Education, Training and Labour

Tel: 506-453-2597

E-mail: dpetlinfo@gnb.caWeb site: http://www2.gnb.ca/content/gnb/en/departments/post-secondary_education_training_and_labour.html**Department of Social Development** (contact information on pg. 33)

Several locations are available throughout the province.

Financial Assistance**Department of Social Development** (contact information on pg. 33) offers various programs to assist with financial need, housing and other concerns related to disability or hospitalization.**Advocacy Resources****Cystic Fibrosis Canada** is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Canada.**Client Advocate Services** exists to inform patients of their rights when dealing with New Brunswick Medicare.

Tel: 506-453-4227

Fax: 506-453-2726

Web site: <http://www.gnb.ca/0394/appeals-e.asp#client>**New Brunswick Human Rights Commission** promotes equality and works to settle complaints of discrimination and harassment. There are regional offices in Campbellton, Moncton and Saint John, as well as offices in Fredericton and Dieppe.

Tel: 506-453-2301

Toll free: 1-888-471-2233

Fax: 506-453-2653

Web site: <http://www.gnb.ca/hrc-cdp/index-e.asp>**Premier's Council on the Status of Disabled Persons** advises the provincial government and the general public on matters relating to the status of persons with disabilities. The council also keeps record of services and resources available for individuals who require them.

Tel: 506-444-3000

Toll free: 1-800-442-4412

Fax: 506-444-3001

E-mail: pcsdp@gnb.caWeb site: <http://www.gnb.ca/0048/>

Newfoundland and Labrador

Clinic

The Janeway Site (paed.) & Health Sciences Centre (adult)* 300 Prince Philip Drive St. John's, Newfoundland and Labrador A1B 3V6 Directors: Dr. M.J. Smith (paed.) Dr. J. Farrell (adult) Clinic Coordinator: Karen Doyle	Clinic	709-777-4389	
	Main	709-777-4222	
	Office	709-777-4326	
	Fax	709-738-4151	

Outreach Clinic

*A combined paediatric/adult outreach clinic is held twice yearly in Gander, NL.

Clinic Resources

Health Professional	Janeway Site (paed.)	Health Sciences Centre (adult)
Physiotherapist	YES	YES
Social Worker	YES	YES
Dietitian	YES	YES
Respirologist/Pulmonologist	*	YES
Gastroenterologist	*	*
Psychologist/Psychiatrist	*	*
Pharmacist	YES	YES
Endocrinologist	*	*

*on referral

Hospital Facilities

Service	Janeway Site (paed.)	Health Sciences Centre (adult)
Rooming in	YES	N/A
Care by parent	NO	N/A
Hostel service	YES	YES
Educational program - e.g. Tutor	YES	NO
Recreational activities - e.g. Play program	YES	NO
Teen Unit	YES	NO
Adult Unit	NO	YES

Patients colonized with *Burkholderia cepacia* complex are not isolated by ward. However, they are not allowed to sleep or receive treatments in the same room at the same time as other, non-colonized, CF patients.

Drug Plan

Newfoundland and Labrador Prescription Drug Program (NLPDP) provides financial assistance for the purchase of eligible prescription medications for those who reside in the province. The NLPDP is “payor of last resort” - if an individual has coverage under the NLPDP and coverage under a private group health insurance plan, bills must go to the private group health insurance provider first. The Select Needs Plan (Cystic Fibrosis) provides 100% coverage for eligible benefits under the CF Program. Therefore, if the full amount is not covered under the private group insurance plan, then NLPDP will cover the remaining balance, as long as it is an eligible benefit.

Eligible benefits include disease-related prescription drugs, enzymes, foods, medical supplies, and equipment, supplied through the Health Sciences Central Supply and Pharmacy. To qualify, individuals must be registered with the CF clinic. Drugs not listed as benefits may be available in certain circumstances through [Special Authorization](#).

Department of Health and Community Services - Prescription Drug Program

Tel: 709-729-6507

Toll free: 1-888-222-0533

E-mail: LIDPinfo@gov.nl.ca

Web site: <http://www.health.gov.nl.ca/health/prescription/index.html>

Nutritional Supplements

All supplements are provided through prescription to the Central Pharmacy. There are standard products (based on the lowest tender) which are appropriate for CF patients.

Equipment and Oxygen

Compressors, percussors, nebulizers, glucoscans, oxygen and postural drainage couches are provided free of charge through the provincial Department of Health and Community Services to individuals with cystic fibrosis. Prescriptions for equipment are written by a CF clinic physician and sent to the Central Pharmacy. Equipment is serviced through the CF clinic, if broken they can be returned to the pharmacy to be replaced at no cost.

http://www.health.gov.nl.ca/health/personsdisabilities/fundingprograms_hcs.html#nlpdp

Homecare

Homecare is available on referral by a CF physician. Additional care is available through community health agencies, at no cost to the individual. Also, a home IV program is available in the St. John's area. Contact the CF nurse coordinator or the Department of Health and Community Services for more details:

Tel: 709-729-4984
 E-mail: healthinfo@gov.nl.ca
 Web site: <http://www.health.gov.nl.ca/health/index.html>

Genetic Counselling

Genetic counselling and testing are available on referral through a CF physician. This service is covered by the provincial health plan. The laboratory in Newfoundland and Labrador that performs genetic testing for CF is:

Janeway Child Health and Rehabilitation Centre
 Genetics Laboratory
 300 Prince Philip Drive
 St. John's, Newfoundland and Labrador A1B 3V6
 Tel: 709-777-4363

Social Support

Contact your local [Cystic Fibrosis Canada chapter](#) or [CF clinic](#) for details on any existing social support networks in the area. There is a chapter in [St. John's](#), with a satellite chapter on the [West Coast](#). Please see the back of this [Guide](#) for a listing of all chapters across Canada.

Educational and Vocational Counselling

LMI Works is a Web site that helps increase access to labour market and career information in the province. It provides information on a wide range of topics including careers, employment, training, human resources, occupations, industries, wages, and provincial and regional labour force trends.

Labour Market Development Division

Department of Human Resources, Labour and Employment

Tel: 709-729-6600

Toll free: 1-800-563-6600

E-mail: labourmarket@gov.nl.ca

Web site: <http://www.lmiworks.nl.ca/>

The Government of Newfoundland and Labrador Office of Employment

Equity for Persons with Disabilities runs various programs aimed for individuals with disabilities, including their “[Opening Doors](#)” employment program.

Tel: 709-729-5881

Toll free: 1-800-950-4414

E-mail: openingdoors@gov.nl

Web site: http://www.exec.gov.nl.ca/exec/pss/disability_supports/

Financial Assistance

Income Support Program provides financial benefits and other services to eligible low income individuals and families to assist in meeting daily living expenses. Contact a [regional office](#) for more information.

E-mail: hreweb@gov.nl.ca

Web site: <http://www.hrle.gov.nl.ca/hrle/income-support/default.html>

Medical Transportation Assistance Program provides financial assistance to residents who incur substantial out-of-pocket travel costs to access specialized insured medical services which are not available in their immediate area of residence and/or within the province.

Claimable expenses include airfare, accommodations purchased from a registered accommodations provider, such as a hostel, hotel, motel and/or registered apartment, scheduled bussing services, and taxis when used in conjunction with commercial air travel. In addition, assistance is provided for individuals who are required to travel in excess of 5,000 km over 12 months with private vehicles. When a patient/family pays out-of-pocket for the cost of registered accommodations, there is a provision for claiming a meal allowance for each night of medically required paid accommodations. Accommodations and/or meals provided by family/friends are not claimable expenses under the program.

E-mail: francinasweetapple@gov.nl.ca

Web site: <http://www.health.gov.nl.ca/health/mcp/travelassistance.html>

Advocacy Resources

Cystic Fibrosis Canada is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Canada.

Human Rights Commission of Newfoundland and Labrador promotes the understanding and acceptance of, and compliance with, the provisions of the Human Rights Act.

Tel: 709-729-2709
Toll free: 1-800-563-5808
Fax: 709-729-0790
E-mail: humanrights@gov.nl.ca
Web site: <http://www.justice.gov.nl.ca/hrc/>

Independent Living Resource Centre provides supports, resources and opportunities for empowerment, which enable persons with disabilities to make informed choices about their lives. It operates out of St. John's, and has resources for individuals and caregivers, friends and family members of individuals with a disability, as well as community organizations, professionals and students.

Tel: 709-722-4031
Toll free: 1-866-722-4031
Fax: 709-722-0147
E-mail: info@ilrc-nl.ca
Web site: <http://www.ilrc-nf.ca/>

Community Sector Council Newfoundland and Labrador is dedicated to advancing the distinct role of the community sector. It fosters volunteerism, social innovation, collaboration, community/social enterprise and knowledge building. The Community Sector Council designs and delivers programs that respond to current community needs, including employment programs for young people and specialized services to support community organizations.

Tel: 709-753-9860
Toll free: 1-866-753-9860
E-mail: csc@csc.nf.net
Web site: <http://www.enVision.ca>

Coalition of Persons with Disabilities (COD) is an advocacy organization concerned with all persons with disabilities, promoting their rights, and raising public awareness of their needs.

Tel: 709-722-7011
Fax: 709-722-4424
E-mail: info@codnl.ca
Web site: <http://www.codnl.ca>

Nova Scotia

Clinics

I.W.K. Health Centre (paed.)*

5850/5980 University Avenue

P.O. Box 9700

Halifax, Nova Scotia B3K 6R8

Director: Dr. D. Hughes

Nurse Coordinator: Paula Barrett

Clinic 902-470-8219

Emergency 902-470-8050

Office 902-470-8219

Fax 902-470-7223

Queen Elizabeth II Health Sciences Centre (adult)

1796 Summer Street

Halifax, Nova Scotia B3H 3A7

Director: Dr. R. Michael

Nurse Coordinator: Fran Gosse

Clinic 902-473-4147

Office 902-422-1708

Fax (office) 902-425-8962

Fax (clinic) 902-473-6202

Outreach Clinics

*The I.W.K. team travels to Sydney, NS; Charlottetown, PEI; and Bathurst and Fredericton, NB, to provide clinical services to patients and families closer to home.

Clinic Resources

Health Professional	I.W.K. Health Centre (paed.)	Q.E.II Health Sciences Centre (adult)
Physiotherapist	YES	YES
Social Worker	YES	YES
Dietitian	YES	YES
Respirologist/Pulmonologist	YES	YES
Gastroenterologist	*	*
Psychologist/Psychiatrist	*	YES
Pharmacist	YES	YES
Endocrinologist	*	*

*on referral

Hospital Facilities

Service	I.W.K. Health Centre (paed.)	Q.E.II Health Sciences Centre (adult)
Rooming in	YES	N/A
Care by parent	NO	N/A
Hostel service	YES	YES
Educational program - e.g. Tutor	YES	NO
Recreational activities - e.g. Play program	YES	YES
Teen Unit	NO	NO
Adult Unit	NO	YES

Patients colonized with *Burkholderia cepacia* complex are not isolated by ward. However, they are not allowed to sleep or receive treatments in the same room at the same time as non-colonized CF patients.

At the Q.E. II Health Sciences Centre, all CF patients have private rooms.

Drug Plan

Nova Scotia provides assistance to eligible residents through various programs to help pay for prescribed medications and supplies listed on the [Nova Scotia Formulary](#). Individuals diagnosed with CF and followed at a CF clinic receive coverage on all drugs and medical equipment.

Pharmacare programs cover drugs that are listed on the Nova Scotia Formulary, and drugs not listed may be covered with special approval.

Nova Scotia Pharmacare Program

Tel: 902-429-6565

Toll free: 1-800-544-6191

Web site: <http://www.gov.ns.ca/health/pharmacare>

Nutritional Supplements

Both the paediatric and adult CF clinic cover oral supplements, tube feeding formulas, equipment and supplies to all qualifying individuals with CF (qualification includes: insurance declined, supplement/tube feed meets at least 50% of their caloric needs). There is no cost to the individual.

Individuals with CF receiving Income Assistance may be eligible to receive special needs funding for assistance with the cost of a special diet, plus the cost of supplements or additional requirements specified by a nutritionist.

Vitamins and enzymes for all individuals with CF are covered under Medical Services Insurance (MSI), which is designed to provide eligible residents with coverage for medically required hospital, medical, dental and optometric services and more.

Medical Services Insurance

Tel: 902-496-7008
 Toll free: 1-800-563-8880
 E-mail: msienquiry@medavie.bluecross.ca
 Web site: <http://www.gov.ns.ca/health/msi>

Equipment and Oxygen

Equipment (such as aerosol machines, nebulizers, facemasks, mouthpiece, oxygen tubing, portable compressors, compressors, PEP Masks, Acapellas, Flutter, ultrasonic humidifiers, etc.) is provided through the provincial Medical Services Insurance (MSI) Program at no cost to individuals with CF.

Contact the clinic coordinator for information on equipment or servicing.

Homecare

Home care services are available through the Continuing Care Branch of the Nova Scotia Department of Health. Services available include: home support, IV therapy, oxygen and more. Some services do come at a charge.

Tel: 902-424-6090
 Toll free: 1-800-225-7225

Home care services are also provided through the Red Cross, municipal homecare and private homemaker services, and are free of charge in cases of financial need. The medical team at the Q.E. II Health Sciences Centre are also able to provide home IV; nutritional supplements; home oxygen; portacaths and per-Q-caths.

<http://www.redcross.ca/article.asp?id=1636&tid=023>

Team members from the I.W.K. Health Centre and the Q.E. II Health Sciences Centre are available for home visits throughout the province. These services are free of charge to any individual diagnosed with CF.

Genetic Counselling

Genetic counselling and testing are available on referral through a CF physician/nurse. This service is covered by the provincial health plan. The laboratory in Nova Scotia, which performs genetic testing for CF is:

I.W.K. Health Centre - Molecular Diagnostic Laboratory
 5850/5980 University Avenue
 Halifax, Nova Scotia B3K 6R8
 Tel: 902-470-8274

Social Support

Contact your local [Cystic Fibrosis Canada chapter](#) or [CF clinic](#) for details on any existing social support networks in the area. In Nova Scotia, Cystic Fibrosis Canada chapters are located in [Halifax](#), [Cape Breton Island](#) and [Yarmouth](#). Please see the back of this [Guide](#) for a listing of all chapters across Canada.

Educational and Vocational Counselling

Department of Labour and Workforce Development has career planning and education programs designed specifically for Nova Scotians.

Toll free: 1-877-223-0888

Web site: <http://www.gov.ns.ca/lwd/careerplanninglabourinformation.asp>

Entrepreneurs with Disabilities Network (EDN) promotes and facilitates entrepreneurship among persons with disabilities.

Tel: 902-426-0561

Toll free: 1-888-576-4444

Fax: 902-426-6530

E-mail: Brianaird@ednns.ca

Web site: <http://www.ednns.ca>

Information on vocational counselling is available through the CF social worker and the provincial rehabilitation counsellor, Department of Community Services.

Financial Assistance

Social assistance may be available through the Nova Scotia Department of Community Services, Employment Support and Income Assistance Program.

http://www.gov.ns.ca/coms/employment/income_assistance/index.html

Stephen Russell Memorial Fund assists persons with CF requiring help with equipment, educational needs, and travel expenses from home to clinic. Cases may be referred by the CF clinic nurse coordinator or social worker.

Advocacy Resources

Cystic Fibrosis Canada is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Canada.

Government of Nova Scotia Human Rights Commission investigates and resolves complaints of discrimination, and provides programs, services and resources on a range of topics. Offices are also located in Digby, New Glasgow and Sydney.

Tel: 902-424-4111
Toll free: 877-269-7699
E-mail: hrcinquiries@gov.ns.ca
Web site: <http://www.gov.ns.ca/humanrights>

Nova Scotia League for Equal Opportunities (LEO) promotes equality for Nova Scotians living with a disability.

Tel: 902-455-6942
Toll free: 866-696-7536
Fax: 902-454-4781
E-mail: nsleo@eastlink.ca
Web site: <http://www.novascotialeo.org>

Nova Scotia Disabled Persons Commission (NSDPC) gives people with disabilities a way to participate in the provincial government policy-making process. It advises policy-makers and program-developers about the needs of people with disabilities and the issues and concerns that affect the lives of people with disabilities.

Tel: 902-424-8280
Toll free: 800-565-8280
Web site: <http://www.gov.ns.ca/disa>

Ontario

Clinics

Children's Hospital of Eastern Ontario (paed.) 401 Smyth Road Ottawa, Ontario K1H 8L1 Directors: Dr. M. Boland Dr. T. Kovesi Nurse Coordinator: Anne Smith	Clinic Emergency Office Fax	613-737-7600 x 2214 613-737-7600 613-737-7600 613-738-4298
Ottawa General Hospital (adult) 501 Smyth Road Ottawa, Ontario K1H 8L6 Director: Dr. S. Aaron Nurse Coordinator: Ena Gaudet	Clinic Emergency Office Fax	613-737-8899 x 78100 613-737-8146 613-737-8899 x 71594 613-739-6807
Hotel Dieu Hospital (paed./adult) 166 Brock Street Kingston, Ontario K7L 5G2 Directors: Dr. R. van Wylick (paed.) Dr. D. Lougheed (adult) Nurse Coordinator: Lisa Smith	Clinic Main Office (adult) Office (paed.) Fax	613-544-3400 x 3147 613-544-3310 613-548-2348 613-544-3400 x 3359 613-544-3559
The Hospital for Sick Children (paed.)* 555 University Avenue Toronto, Ontario M5G 1X8 Director: Dr. M. Solomon Clinical Nurse Specialist/Nurse Practitioner: Louise Taylor	Clinic Main Office Fax (clinic)	416-813-5826 416-813-1500 416-813-6167 416-813-6246
St. Michael's Hospital (adult)* 30 Bond Street Toronto, Ontario M5B 1W8 Director: Dr. E. Tullis Nurse Practitioner: Anna Tsang	Clinic Emergency For Appt. Office Fax (clinic)	416-864-5409 416-864-5431 416-864-5764 416-864-5406 416-864-5651
Hamilton Health Sciences Corporation (paed.) McMaster Children's Hospital 1200 Main Street West, 2nd Floor, 2G Hamilton, Ontario L8N 3Z5 Director: Dr. L. Pedder Nurse Coordinator: Val Carroll Research Coordinator: Rosamund Hennessey	For Appt. Emergency Office Fax (clinic) Coordinator Research	905-521-2100 x 78520 905-521-2100 905-521-2100 x 73508 905-524-5707 905-521-2100 x 73086 905-912-2212

<p>Hamilton Health Sciences Corporation (adult) McMaster University Medical Centre 1200 Main Street West, Room 3V2 Hamilton, Ontario L8N 3Z5 Director: Dr. A. Freitag Nurse Coordinator: Kelly Campbell Research Coordinator: Rosamund Hennessey</p>	<p>Clinic 905-521-2100 x 75711 Emergency 905-521-2100 Office 905-521-2100 x 76216 Fax (clinic) 905-521-5073 Coordinator 905-521-2100 x 75711 Research 905-912-2212</p>
<p>London Health Sciences Centre (paed.)** Children's Hospital, VH PMDU Zone E-400 800 Commissioners Road East London, Ontario N6A 5W9 Directors: Drs. B. Lyttle and A. Price Paediatric Nurse Case Manager: Erin Fleischer</p>	<p>Clinic 519-685-8500 x 52692 Emergency 519-685-8141 Office 519-433-2242 x 52032 Fax 519-685-8130</p>
<p>London Health Sciences Centre (adult)** South Street Hospital 375 South Street London, Ontario N6A 4G5 Director: Dr. N. Patterson Adult Nurse Case Manager: Tracy Gooyers</p>	<p>Clinic 519-685-8500 x 55186 Emergency 519-685-8141 Office 519-667-6548 Fax (clinic) 519-685-8130</p>
<p>Grand River Hospital (paed.) Kitchener-Waterloo Site 835 King Street West Kitchener, Ontario N2G 1G3 Director: Dr. L. Pineau Nurse Coordinator: Lori Peterson</p>	<p>Clinic 519-749-4300 x 3716 Main 519-742-3611 Office 519-741-8660 Fax (clinic) 519-749-4317</p>
<p>St. Mary's General Hospital (adult) 911 Queen's Boulevard Kitchener, Ontario N2M 1B2 Director: Dr. M. Jackson Nurse Coordinator: Lori Peterson</p>	<p>Clinic 519-749-4300 x 3716 Main 519-744-3311 Office 519-749-6868 #1 Fax (clinic) 519-749-4317</p>
<p>Windsor Regional Hospital (paed.) 1995 Lens Avenue Windsor, Ontario N8W 1L9 Director: Dr. L. Morgan Clinic Coordinators: Sue Grebe and Michelle Murray</p>	<p>Clinic 519-254-5577 Emergency 519-254-5577 x 52222 Office 519-944-9924 Fax (office) 519-944-7282</p>
<p>Sudbury Regional Hospital (paed./adult) 41 Ramsey Lake Road Sudbury, Ontario P3E 5J1 Director: Dr. V. Kumar Nurse Coordinator: Sharri-Lynne Zinger</p>	<p>Clinic 705-522-2200 x 3263 Main 705-523-7100 Office 705-674-1499 Fax (clinic) 705-523-7288</p>

Outreach Clinics

*A health care team from CF clinics at The Hospital for Sick Children (HSC) and St. Michael's Hospital (SMH) participate in outreach clinics in Thunder Bay and Sudbury, ON.

**Clinic staff members from the London Health Sciences Centre (LHSC) participate in an outreach clinic in Sault Ste. Marie, ON.

Clinic Resources

Health Professional	CHEO	OGH	HDH	HSC	SMH	HHSC		LHSC		KWHC		WRH	SRH
						paed.	adult	paed.	adult	paed.	adult		
Physiotherapist	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Social Worker	YES	YES	YES	YES	YES	YES	NO	YES	YES	YES	YES	YES	YES
Dietitian	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Respirologist/ Pulmonologist	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	*	YES
Gastroenterologist	YES	*	*	YES	YES	*	YES	*	*	*	*	*	*
Psychologist/ Psychiatrist	*	*	*	YES	YES	*	*	*	YES	*	*	NO	*
Pharmacist	YES	YES	*	YES	YES	*	*	*	YES	YES	YES	YES	YES
Endocrinologist	*	*	*	*	YES	*	*	*	*	*	YES	*	*
Respiratory Therapist	YES	*	YES	N/A	YES	*	*	N/A	N/A	YES	YES	N/A	YES

*on referral **pediatric clinic provides Life Services

Hospital Facilities

Service	CHEO	OGH	HDH	HSC	SMH	HHSC	LHSC	KWHC	WRH	SRH
Rooming in	YES	YES	YES	YES	NO	YES*	YES	YES	YES	YES
Care by parent	YES	YES	YES	YES	NO**	YES	YES	YES	YES	YES
Hostel service	YES	YES	YES	YES	NO	YES	YES	NO	NO	NO
Educational program	YES	YES	YES	YES	NO	YES	YES	NO	YES	YES
Play program	YES	YES	YES	YES	NO	YES	YES	YES	YES	YES
Teen Unit	YES	NO	NO	YES	NO	NO	NO	NO	YES	NO
Adult Unit	NO	NO	YES	NO	YES	YES	YES	NO	YES	NO

*paediatrics only; all patients receive private rooms as available and as per patient's isolation issues

**assessed on a case-by-case basis

Adults in London are hospitalized at London Health Sciences Centre, Victoria Campus under Dr. C. George, Dr. N. Paterson, or Dr. D. McCormack.

Patients colonized with *Burkholderia cepacia* complex are segregated from other patients. At HHSC, CHEO, HDH, SMH, and KWHC, CF patients will not be placed in the same room.

Drug Plan

Special Drugs Program covers the full cost of certain out-patient drugs used in the treatment of specific conditions, including cystic fibrosis and organ transplant recipients. To qualify for coverage, an individual must be an Ontario resident (with valid Ontario Health Insurance Plan (OHIP) coverage), be diagnosed with CF, be followed by a designated CF clinic, and obtain his/her medications from a designated hospital pharmacy.

Tel: 1-866-532-3161

Web site: <http://www.health.gov.on.ca/en/public/programs/drugs/programs/sdp.aspx>

Trillium Drug Program (TDP) helps individuals and families who have high prescription drug costs in relation to their income. Similar to the Ontario Drug Benefit Program (see below), the TDP provides coverage for prescription drug products listed on the [Formulary](#). TDP applicants must pay a quarterly or pro-rated deductible that is based on family income and size before they are eligible to receive drug coverage. [Trillium Drug Program Application Forms and Guides](#) are available at local pharmacies, or by contacting:

Tel: 416-642-3038

Web site: <http://www.health.gov.on.ca/english/public/pub/drugs/trillium.html>

Individuals, who are registered in the Trillium Drug Program, receive professional home care services, reside in a home designed for long-term care, are on social assistance and/or are over 65 years of age, are eligible for the **Ontario Drug Benefit Program (ODB)**. This program covers most of the cost of prescription drugs listed in the Formulary. Drugs that are not listed in the formulary may be covered through the [Exceptional Access Program](#); requests for coverage under this program are assessed on a case-by-case basis.

<http://www.health.gov.on.ca/en/public/programs/drugs/programs/odb/odb.aspx>

Nutritional Supplements

Certain enzymes, vitamins, and nutritional supplements are covered by the [Special Drugs Program](#), provided they are obtained from a CF clinic, CF clinic hospital pharmacy, or the Specialty Food Shop, which is located in [The Hospital for Sick Children](#) (Toronto).

Tel: 416-813-5294

Web site: <http://www.specialtyfoodshop.com>

Equipment and Oxygen

Compressors, percussors, nebulizers, postural drainage boards, oxygen, and oxygen equipment are provided to individuals with CF, on a cost-sharing basis through the **Assistive Devices Program (ADP)** and **Home Oxygen Program (HOP)**. Generally, ADP will pay up to 75% of the vendor's selling price up to a set maximum amount for equipment for qualified individuals. Eligibility includes any Ontario resident who has a long-term physical disability and a valid Ontario Health card issued in their name.

The portion of the costs not covered by ADP may be covered by a private health insurance plan. If the individual requiring the equipment is receiving benefits from Ontario Works (OW), Ontario Disability Support Program (ODSP) or Assistance for Children with Severe Disabilities (ACSD), the equipment vendor may be able to bill ADP for a higher amount, therefore reducing or eliminating the cost to the individual. ADP will contribute towards the replacement cost of equipment that is no longer working or cannot be repaired, based on a replacement period schedule, with times ranging between two to five years.

Assisted Devices Program

Tel: 416-327-8804

Toll free: 1-800-268-6021

Web sites: http://www.health.gov.on.ca/english/public/program/adp/adp_mn.html
<http://www.health.gov.on.ca/english/public/pub/adp/oxygen.html>

Homecare

In-home health services are provided through **Ontario Community Care Access Centres (CCAC)**. Services provided include: homecare nursing, physiotherapy, occupational therapy, speech and language therapy, palliative care, dietetic services, social work and some homemaker services. There are 14 CCAC jurisdictions across Ontario. CCAC managers assess an individual's need for service on a case-by-case basis; anyone can refer themselves, or a friend, family member or a patient to CCAC service.

Tel: 310-2222

Web site: <http://www.ccac-ont.ca>

Genetic Counselling

Genetic counselling and testing are available on referral through a CF physician. This service is covered by the provincial health plan for residents of Ontario. There are currently five laboratories in Ontario which perform genetic testing for CF:

<p>Children's Hospital of Eastern Ontario Eastern Ontario Regional Genetics Program 401 Smyth Road Ottawa, Ontario K1H 8L1 Tel: 613-737-2275</p>	<p>North York General Hospital Genetics Program 4001 Leslie Street Toronto, Ontario M2K 1E1 Tel: 416-756-6345</p>
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<p>The Hospital for Sick Children Paediatric Laboratory Medicine 555 University Avenue Toronto, Ontario M5G 1X8 Tel: 416-813-6497</p>	<p>London Health Sciences Centre Molecular Diagnostic Laboratory 800 Commissioners Road East London, Ontario N6C 2V5 Tel: 519-685-8140</p>
<p>McMaster Children's Hospital Clinical Genetics Program 1200 Main St. W. Hamilton, Ontario L8N 3Z5 Tel: 905-521-5085</p>	

Newborn Screening

Ontario screens newborns for cystic fibrosis. Please refer to Cystic Fibrosis Canada's [Newborn Screening for Cystic Fibrosis](#) brochure for further information.

Social Support

Contact the local [Cystic Fibrosis Canada chapter](#) or [CF clinic](#) for details on existing social support networks in the area. In Northern Ontario, Cystic Fibrosis Canada chapters are located in [North Bay](#), [Sault Ste. Marie](#), [Sudbury](#) and [Thunder Bay](#). In Central Ontario, chapters are located in [Durham](#), [Hamilton](#), [Niagara](#), [Peel & District](#) and [Toronto](#). In Eastern Ontario, there are chapters in [Cornwall](#), [Kingston](#), [Ottawa](#) and [Peterborough](#). In Western Ontario, chapters are active in [North Perth](#) (H.O.P.E.), [Sarnia](#), [London](#), [Kitchener-Waterloo](#) and [Essex-Kent](#). Please see the back of this [Guide](#) for a listing of all chapters across Canada.

Educational and Vocational Counselling

Employment Ontario provides a variety of options for individuals seeking a job or job training and skill development. Employment Ontario funds local Employment Assistance and Resource Centres, local Job Banks, Skill Development courses and wage subsidies.

Tel: 1-800-387-5514

Web site: <http://www.tcu.gov.on.ca/eng/employmentontario/>

Ontario Disability Support Program (ODSP) aims to assist individuals with a disability with income support, as well as employment supports including (but not limited to): job coaching; on-the-job training; transportation assistance; and specialized skill training. The program may also include accommodation and basic living expenses as well as prescription drugs and basic dental care. Employment supports provide goods and services to eligible people with disabilities to help overcome barriers to employment.

Ontario Works (OW) Program provides financial and employment assistance to people in temporary financial need. To be eligible applicants must be residents of Ontario. Eligibility is based on an assessment of financial need and an agreement to participate in employment activities. Health coverage is limited to items covered

by the Ontario Drug Benefit plan. Drug cards are issued for one month only. Ontario Works may provide coverage for the Assistive Devices Program (ADP) assessment fee and the consumer contribution if these costs are not otherwise reimbursed.

Individuals receiving social assistance under a program such as the ODSP or OW, may also apply to the **Ontario Student Assistance Program (OSAP)** and/or receive loan forgiveness through the [Repayment Assistance Plan](#) or [Severe Permanent Disability Benefit](#).

For more information on these programs contact:

Ministry of Community and Social Services

Tel: 416-325-5666

Toll free: 1-888-789-4199

Ontario Works

<http://www.mcsc.gov.on.ca/en/mcsc/programs/social/ow/index.aspx>

Ontario Disability Support Program

<http://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/>

Ontario Student Assistance Program

<https://osap.gov.on.ca/OSAPPortal/>

Financial Assistance

Northern Health Travel Grants Program grants help defray the travel costs for qualifying Northern Ontario residents who must travel at least 100 kilometres one-way in order to receive specialized health services. Travel grants will be paid based on a mileage rate of 41 cents per kilometre with a 100 kilometre deductible.

Tel: 1-800-461-4006

Web site: <http://www.health.gov.on.ca/english/public/pub/ohip/northern.html>

Ministry of Children and Youth Services has a Web site listing programs available for children with special needs. It provides parents and caregivers with information about services funded and/or offered by the Ontario Government for children who need specialized services to participate in daily living activities.

Tel: 1-866-821-7770

Web site: <http://www.children.gov.on.ca/>

Assistance for Children with Severe Disabilities (ACSD) Program helps parents with some of the extra costs of caring for a child who has a severe disability. Eligibility is based on the income level of the parent/guardian and on the degree of impairment by the medical condition. If a child has cystic fibrosis and has functional restrictions as a result of the chronic illness, the parent/guardian may be eligible for the ACSD Program. Financial assistance ranges from \$25 - \$440 per month. Contact your local [regional office](#) and ask for an application form.

<http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/disabilities/index.aspx>

Special Services At Home (SSAH) is a program that helps children with physical disabilities to live at home with their families. The program provides some financial

support towards family relief and support. SSAH is not income based; however, to be eligible the illness of the chronically-ill child must result in an on-going functional limitation and require support beyond what is a normal family responsibility.

<http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/specialservices/index.aspx>

Through the Ministry of Revenue, individuals with disabilities may be eligible for non-refundable tax credits on Form ON428 – Ontario Tax, of the personal income tax return.

Tel: 1-866-ONT-TAXS (1-866-668-8297)
Web site: <http://www.rev.gov.on.ca/en/credit/index.html>

Jennifer Ashleigh Foundation provides financial support for costs surrounding a child's (an individual under twenty-one years of age) illness. The Jennifer Ashleigh Foundation serves Ontario residents, and will consider requests for emergency financial relief, medical treatment not covered by OHIP, parental relief, educational supports and some recreational programs.

Tel: 905-852-1799
Web site: <http://www.jenniferashleighfoundation.ca>

Lions Foundation of Manitoba and Northwestern Ontario assists recipients with non-medical costs such as travel and accommodations, and provides financial assistance for special equipment needed by the recipients and not covered by government funding.

Tel: 204-772-1899
Web site: <http://www.eyebankmanitoba.com/>

Advocacy Resources

Cystic Fibrosis Canada is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Canada.

ARCH Disability Law Centre provides online resources for individuals with a disability seeking legal information or advice.

Tel: 416-482-8255
Toll free: 1-866-482-2724
Web site: <http://www.archdisabilitylaw.ca/>

Centre for Independent Living in Toronto (CILT) works to promote the attainment of optimal independent living for individuals with a disability living in Toronto. They provide services as well as a database of service organizations.

Tel: 416-599-2458
E-mail: cilt@cilt.ca
Web site: <http://www.cilt.ca>

Prince Edward Island

Clinic

While there is no formal CF clinic located on Prince Edward Island, an outreach clinic from the I.W.K. Health Centre in Halifax, Nova Scotia, is held in Charlottetown twice each year for paediatric patients. Contact the nurse coordinator at the I.W.K. Health Centre in Halifax for details:

I.W.K. Health Centre (paed.)
Director: Dr. D. Hughes
Nurse Coordinator: Paula Barrett

Clinic	902-470-8219
Emergency	902-470-8050
Office	902-470-8219
Fax	902-470-7223

Adults in PEI are able to see a respirologist on a regular basis upon referral through their family physician.

For full clinic services, patients may travel to the Queen Elizabeth II Health Services Centre (adult) or I.W.K. Health Centre (paediatric) in Halifax. Please refer to the Nova Scotia section of this *Guide* for further information regarding these clinics.

Drug Plan

Some CF-related medications are covered by the provincial government under the [Health PEI Cystic Fibrosis Program](#) for persons eligible for PEI Medicare, diagnosed with CF, and registered with the program. It covers basic CF-related prescription and non-prescription medications and includes antibiotics, enzymes, bronchodilators, vitamins and necessary intravenous solutions, which are dispensed from the provincial pharmacy.

[Health P.E.I. Transplant Program](#) pays for approved immunosuppressant medications for eligible persons. A physician or specialist must register the client in the program on their behalf.

PEI Pharmacare

Tel: 902-368-4947
Toll free: 1-877-577-3737

Health PEI

Tel: 902-368-6130
E-mail: healthinput@gov.pe.ca
Web site: <http://www.healthpei.ca/>

Nutritional Supplements

Vitamins are provided at no charge, through the Cystic Fibrosis Program. However, nutritional supplements are not; they may be available to individuals who qualify for the [Disability Supports Program](#). For others, they may be covered through private insurance.

Tel: 902-368-5996
 Web site: <http://www.gov.pe.ca/hss/peidsp/>

Equipment and Oxygen

Contact the Respiratory Division at the [Queen Elizabeth Hospital](#) in Charlottetown for information on equipment maintenance and servicing: 902-894-2111.

Oxygen costs are covered through the [Health PEI Home Oxygen Program](#) for persons prescribed oxygen by a specialist and who meet clinical criteria, and are eligible for PEI Medicare. Once approved, clients deal through oxygen suppliers. There are two private companies (Medigas and VitalAire) that provide oxygen service.

Medigas

Tel: 1-866-446-6302
 Web site: <http://www.medigas.com/>

VitalAire

Tel: 1-800-664-6410
 Web site: <http://www.vitalaire.com/en/home.html>

Homecare

PEI Home Care Program provides health care and support services including assessment, care coordination, nursing, personal care, respite, occupational and physical therapies, and community support services. Home care and support services are provided based on assessed need.

<http://www.healthpei.ca/homecare>

Souris: 902-687-7096	Montague: 902-838-0786	Charlottetown: 902-368-4790
Summerside: 902-888-8440	O'Leary: 902-859-8730	Provincial Home Care Director: 902-888-8005

Physiotherapy services are offered on an outpatient basis. Referrals can be made by a physician to most hospital-based ambulatory services at no cost, or through private clinics at an estimated cost of \$55 per hour for an initial visit and \$45 for additional visits. These costs are generally covered by private insurance.

Social Support

Contact the [Prince Edward Island Cystic Fibrosis Canada chapter](#) in Mount Stewart for details on the existing social support network in the area. Please see the back of this [Guide](#) for a listing of all chapters across Canada.

Educational and Vocational Counselling

Employment Development Agency assists individuals seeking employment opportunities by: providing access to training; identifying and developing meaningful work projects within the public sector and the community; and applying principles of fairness in the provision of employment opportunities.

Tel: 902-838-0910
 Web site: <http://www.gov.pe.ca/fa/eda-info/dg.inc.php3>

PEI Council of People with Disabilities offers a number of employment and career related services to people with disabilities.

Tel: 902-892-9149
 E-mail: peicod@peicod.pe.ca

SkillsPEI manages the delivery of training and skills development programming funded by the Canada-PEI Labour Market Development Agreement (LMDA) and Labour Market Agreement (LMA).

Tel: 1-877-491-4766
 Web site: <http://www.skillspei.com>

Full-time student loan funding in PEI is based on two programs, the **Canada Student Loans Program** and the **Prince Edward Island Student Loans Program**. For more information, contact:

Tel: 902-368-4640
 Web site: <http://www.gov.pe.ca/ial/index.php3?number=1000717>

Financial Assistance

Financial Assistance Program provides full coverage of the cost of approved prescription and non-prescription medications that are listed on the [PEI Drug Formulary](#). To qualify for coverage, individuals must be eligible for financial assistance under the [Social Assistance](#) Act and Regulations and be eligible for PEI Medicare.

Tel: 902-368-4947 or 1-877-577-3737
 Web site: <http://www.healthpei.ca/index.php3?number=1026281&lang=E>

PEI Disability Support Program (DSP) is a social and financial support program that assists with personal planning and helps meet the needs related to an individual's disability. These supports are needs-based, and they are not intended to provide income. For more information, see the [Disability Support Program Policy Manual](#), or contact:

Tel: 902-368-5996
 Web site: <http://www.gov.pe.ca/hss/peidsp/>

Advocacy Resources

Cystic Fibrosis Canada is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Canada.

P.E.I. Council of People with Disabilities speaks out on issues such as housing, education, employment, transportation, human rights and access to support services.

Tel: 902-892-9149
E-mail: peicod@peicod.pe.ca

Prince Edward Island Human Rights Commission administers and enforces the Prince Edward Island Human Rights Act. The Act establishes a complaint process for the investigation and adjudication of complaints. The Commission also develops programs of public information and education about human rights.

Tel: 902-368-4180
Toll free: 1-800-237-5031
Web site: <http://www.gov.pe.ca/humanrights>

PEI Coalition on Organ and Tissue Donation works to promote awareness of the need for organ and tissue donation. The Coalition is a partnership of PEI businesses, health organizations, hospitals, and the Department of Health and Wellness.

Tel: 902-894-2007
Web site: <http://www.gov.pe.ca/infopei/index.php3?number=50850&lang=E>

Quebec

Clinics

Centre de santé et de services sociaux de Gatineau (adult)

116, boul. Lionel Émond	Clinic	819-595-6053
Hull, Québec J8Y 1W7	Emergency	819-771-8367
Director: Dr. G. Côté	Office	819-595-6053
Nurse Coordinator: Line Lemieux	Fax (office)	819-595-6081

Centre hospitalier régional de Rimouski (paed./adult)

150, avenue Rouleau	Clinic	418-724-3000 x 8768
Rimouski, Québec G5L 5T1	Office	418-724-4221
Director: Dr. S. Goulet	Fax	418-725-3025
Nurse Coordinator: Lili Henley-Boucher		

Centre hospitalier de l'Université Laval (paed.)

2705, boul. Sir Wilfrid Laurier	Clinic	418-656-4141 x 47506
Sainte-Foy, Québec G1V 4G2	Emergency	418-656-4141
Directors: Dr. G. Rivard	Office	418-654-2282
Dr. P. Daigneault	Fax	418-654-2137
Nurse Coordinator: Manon Roussin		

Institut Universitaire de Cardiologie et de Pneumologie de Québec (adult)*

Hôpital Laval	Clinic	418-656-8711 x 3538
2725, chemin Sainte-Foy	Office	418-656-8711
Québec, Québec G1V 4G5	Fax	418-656-4775
Director: Dr. L. Bilodeau		
Nurse Coordinator: Ève Routhier		

Centre universitaire de santé de L'Estrie (paed./adult)

3001, 12e Av. Nord	Clinic	819-346-1110 x 12820
Sherbrooke, Québec J1H 5N4	Emergency	819-346-1110
Directors: Dr. L. Rivard (paed.)	Office (paed.)	819-346-1110
Dr. A. Cantin (adult)	Office (adult)	819-346-1110 x 14893
Nurse Practitioner: Josée Lessard	Fax (clinic)	819-820-6487

Centre de santé et de services sociaux de Chicoutimi (paed./adult)

305, rue St-Vallier, C.P. 33	Clinic	418-541-1037
Chicoutimi, Québec G7H 5H6	Emergency	418-541-1037
Directors: Dr. M. Milot	Office	418-549-1034
Dr. C. Allard	Fax (office)	418-541-1134
Nurse Coordinators: Chantale Martineau Maryse Bandet		

Centre hospitalier universitaire Sainte-Justine (paed.)

3175, chemin de la Côte-Ste-Catherine
 Montréal, Québec H3T 1C5
 Director: Dr. J.-É. Marcotte
 Nurse Coordinators: Isabelle Tellier
 Véronique Fauvel

Clinic 514-345-4931 x 6045
 Emergency 514 345-4931 x 4919
 Office 514 345-4724
 Fax (office) 514-345-4804

Hôtel-Dieu de Montréal (adult)

3840, rue St-Urbain
 Montréal, Québec H2W 1T8
 Director: Dr. A. Lavoie
 Nurse Coordinators: Stéphanie Turcotte
 Yung-Chun Chou

Clinic 514-890-8000 x 14802
 Emergency 514-890-8000 x 14444
 Office 514-890-8000 x 1566
 Fax 514-412-7002

Montreal Chest Institute (adult)

3650, rue Saint-Urbain
 Montréal, Québec H2X 2P4
 Director: Dr. E. Matouk
 Nurse Coordinator: Noel Dowell

Clinic 514-934-1934 x 32121
 Emergency 514-934-1934 x 32567
 Office 514-934-1934 x 32559
 Fax 514-843-2070

The Montreal Children's Hospital (paed.)*

2300, rue Tupper
 Montréal, Québec H3H 1P3
 Director: Dr. L. Lands
 Nurse Coordinator: Sophie Vallée-Smejda

Clinic 514-412-4400 x 22643
 Emergency 514-412-4400
 Office 514-412-4444
 Fax 514-412-4364

Centre de santé et de services sociaux de Rouyn-Noranda (paed./adult)

4, 9e Rue
 Rouyn-Noranda, Québec J9X 2B2
 Directors: Dr. C. Popa
 Dr. L. Perreault
 Nurse Coordinator: Micheline Perron

Clinic 819-764-5131 x 43886
 Emergency 819-764-5131
 Office 819-762-0995
 Fax 819-797-6837

Outreach Clinics

*A health care team from CF clinics at Hôpital de Montréal pour Enfants (HME) and Hôpital Laval (HL) participate in outreach clinics in Rouyn-Noranda and Baie-Comeau, QC.

Clinic Resources

Health Professional	CSSG	CHRR	CHUL	HL	CUSE	CSSSC	CHUSJ	HDM	MCI	MCH	CSSRN
Physiotherapist	YES	YES	YES	*	YES	YES	YES	*	YES	YES	*
Social Worker	NO	YES	YES	YES	YES	NO	YES	YES	YES	YES	YES
Dietitian	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Respirologist/ Pulmonologist	YES	YES	YES	*	YES	YES	YES	YES	YES	YES	YES (adults) NO (paed.)
Gastroenterologist	*	*	YES	*	YES	YES	YES	YES	*	YES	*
Psychologist/ Psychiatrist	NO	YES	YES	YES	YES	YES	YES	YES	*	*	*
Pharmacist	YES	*	YES	YES	YES	YES	YES	YES	YES	*	YES
Endocrinologist	YES	*	YES	NO	YES	YES	YES	*	*	YES	*
Respiratory Therapist	YES	YES	*	YES	*	YES	YES	*	YES	*	YES

*on referral

Hospital Facilities

Service	CSSG	CHRR	CHUL	HL	CUSE	CSSSC	CHUSJ	HDM	MCI	MCH	CSSRN
Rooming in	NO	YES	YES	YES	YES	YES	YES	N/A	N/A	YES	YES
Care by parent	NO	NO	NO	YES	NO	NO	YES	N/A	N/A	NO	NO
Hostel service	NO	YES	YES	NO	YES	YES	YES	NO	NO	YES	NO
Educational program	NO	YES	YES	YES	YES	YES	YES	N/A	N/A	YES	NO
Play program	NO	YES	YES	NO	YES	YES	YES	N/A	N/A	YES	NO*
Teen Unit	NO	NO	NO	NO	NO	YES	YES	N/A	N/A	NO	NO*
Adult Unit	YES	NO	YES	NO	YES	YES	NO	YES	YES	NO	NO

At CSSSC, adults are hospitalized in the pulmonology department.

Patients colonized with *Burkholderia cepacia* complex are given private rooms at all institutions.

Drug Plan

[Quebec Ministry of Health and Social Services](#) requires that all residents be covered either by [personal or group insurance](#), or by the [government's program](#). The provincial government program involves the payment of premiums ranging from \$0 to \$600 depending on net family income. In addition, individuals must pay a monthly deductible, which varies, depending on the individual's circumstances.

Certain individuals do not pay anything when purchasing insured drugs, including:

- Children of insured persons*
- Holders of a [claim slip](#) issued by the Minister of Employment and Social Solidarity
- Persons age 65 or over receiving 94% to 100% of [Guaranteed Income Supplement \(GIS\)](#)

*Children whose parents are covered by the public plan benefit from their parent's plan until their 18th birthday. From age 18 to 25 inclusive, children may remain covered by the public plan if they are full-time students, do not have a spouse, and live with their parents.

Most CF drugs are covered by the provincial program. Some medications are available to individuals with CF through [médicaments d'exception](#), as a special exception medication, if prescribed by a CF physician.

Quebec: 418-646-4636
 Montreal: 514-864-4311
 Toll free: 1-800-561-9749
 Web site: <http://www.ramq.gouv.qc.ca>

Equipment and Oxygen

Equipment such as percussors, compressors and nebulizers are available on short-term loans from some CF clinics and chapters. Contact the local nurse coordinator for details on availability and servicing. Equipment costs are covered for individuals/families on social assistance. Individuals with private insurance generally have a percentage of the cost covered by the insurance company according to their policy.

In the majority of cases, oxygen expenses are paid by the individual, who is reimbursed by private insurance or social assistance. In some cases oxygen may be covered by special hospital arrangements.

Homecare

Homecare is provided through [Centres de santé et de services sociaux](#) (CSSSs) or local community service centres. Homecare is available to all Quebec residents, who are unable to meet their essential care needs and have a medical prescription. Nursing and physiotherapy services are available in some areas of the Province of Quebec. There are varying cost arrangements. Some clinics offer a home visit by a nurse.

<http://www.gouv.qc.ca>

Genetic Counselling

Genetic counselling and testing are available on referral through a CF physician. This service is funded in part by [Fonds de recherche en santé du Québec](#) (FRSQ) and in part by the hospital budget. The one laboratory in Quebec that performs genetic testing for CF is:

Montreal Children's Hospital - [A/S Laboratoire génétique moléculaire](#)
Tel: 514-412-4400 x 23298

Individuals at Gatineau may be referred to the Children's Hospital of Eastern Ontario for genetic counselling (refer to Ontario section).

Social Support

Contact [Cystic Fibrosis Quebec](#), the provincial association of Cystic Fibrosis Canada, the local [Cystic Fibrosis Canada chapter](#), or [CF clinic](#) for details on the existing social support network in the area. In Eastern Quebec, chapters are located in [Bas-Saint-Laurent/Gaspésie](#), [Charlevoix-Ouest](#), [La Malbaie](#), [Côte-Nord](#), [Lac-Saint-Jean](#), [Québec City](#) and [Saguenay](#). In Western Quebec, chapters exist in [Mauricie-Centre du Québec](#), [Estrie](#), [Montréal](#) and [Outaouais](#). Please see the back of this [Guide](#) for a listing of all Cystic Fibrosis Canada chapters.

Cystic Fibrosis Quebec
Tel: 514-877-6161
Toll free: 1-800-363-7711
Web site: www.fibrosekystiquequebec.ca

Adult Cystic Fibrosis Committee of Quebec (ACFCQ) runs various services and support systems for the CF community, and offers information and resources.

Tel: 514-288-3157
Toll free: 1-800-315-3157
E-mail: cpafk@videotron.ca
Web site: <http://www.cpafk.qc.ca>

Educational and Vocational Counselling

Special employment benefits are available to CF individuals through the **Office of Handicapped Persons of Quebec (OPHQ)**. OPHQ and the Ministry of Employment and Social Solidarity have created the site **Together at Work** containing resources and information for people with disabilities and employers.

Service de développement d'employabilité de la Montérégie (SDEM), and **Service externe de Main-d'œuvre (SEMO)**, provide professional training programs that are adapted to persons with disabilities. The programs provide qualified candidates with vocational guidance, resumé preparation and interview skills. They provide services to employers such as providing needs assessment services, pre-selecting candidates and negotiating employment subsidies.

**Office des personnes handicapées du Québec/
Office of Handicapped Persons of Quebec (OPHQ)**

Tel: 1-800-567-1465
Toll free: 1-800-567-1477
Web site: <http://www.ophq.gouv.qc.ca>

Together at Work

Tel: 418-643-4721
Toll free (Quebec): 1-888-643-4721
Web site: <http://www.ensembleautravail.gouv.qc.ca/>

SDEM-SEMO

Tel: 450-674-1812 (SDEM)
450-646-1595 (SEMO)
Toll free: 1-800-646-6096
Web site: <http://www.sdem-semb.org/>

Financial Assistance

Services Québec (available in French only) provides persons with disabilities and their families with information on the programs, services, and resources available to persons with disabilities and their families, and lets them know the procedures to access them. It provides financial assistance for the integration of a pre-school child with special care needs into the school system. This fund also provides support for respite to families of special needs children.

Quebec: 418-644-4545
Montreal: 514-644-4545
Toll free (Quebec): 1-877-644-4545
Web site: <http://www.personneshandicapees.info.gouv.qc.ca/fr/index.asp>

The province of Quebec offers monthly allowances for children with disabilities. The allowance for children with disabilities helps parents or their substitutes provide for the special needs of a child younger than 18 years of age who has a serious and permanent physical or mental disability and whose condition requires setting up specialized measures in matters of treatment, rehabilitation, remedial instruction and/or schooling. To qualify, the illness or disability must prevent the child from functioning at a normal level.

Régie des rentes du Québec (Quebec Pension Plan, QPP) administers a refundable tax credit for child assistance. The tax credit is paid directly to families and has two components: a child assistance payment and a supplement for handicapped children.

Provincial tax credits for disabled individuals are available to eligible residents of Quebec. Adults with CF who worked a certain number of years and contributed to the *Régime des rentes du Québec*, and who are considered disabled by the QPP can obtain disability benefits.

Quebec: 418-643-5185
Montreal: 514-873-2433
Toll free: 1-800-463-5185
Web site: <http://www.rrq.gouv.qc.ca/fr/>

Allowance for Special Needs Program provides financial assistance to students with CF who meet the disability criteria.

Tel: 418-646-6006

Toll free: 1-866-946-6006

Web site: <http://www.afe.gouv.qc.ca/en/autresProgrammes/allocationsBesoins.asp>

Advocacy Resources

Cystic Fibrosis Canada is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Quebec.

[Adult Cystic Fibrosis Committee of Quebec \(ACFCQ\)](#) advocates on issues of importance to individuals with CF in Quebec. See contact information listed in the Social Support section.

Office des personnes handicapées du Québec (OPHQ) works to individually assess and work with individuals with disabilities and their families to help meet their needs in terms of school, work and social integration. The office will also refer individuals and families to the most appropriate resources. Regional offices are located in Rimouski, Chicoutimi, Trois-Rivières, Sherbrooke, Québec, Bas St. Laurent, Gaspé, Montréal, St. Jérôme, Longueuil, Hull, Rouyn, and Baie-Comeau. The main office is located in Drummondville.

Tel: 1-800-567-1465

Web site: <http://www.ophq.gouv.qc.ca>

Saskatchewan

Clinics

Regina General Hospital (paed.)

1440-14th Avenue
Regina, Saskatchewan S4P 0W5
Director: Dr. B. Holmes
Nurse Coordinator: Kenda Power

Clinic 306-766-4289
Emergency 306-766-4213
Main 306-766-4444
Office 306-352-4900
Fax 306-766-4946

Royal University Hospital (paed./adult)

103 Hospital Drive
Saskatoon, Saskatchewan S7N 0W8
Directors: Dr. J. Brusky (paed.)
Dr. J. Gjevre (adult)
Nurse Coordinators: Lorna Kosteniuk (paed.)
Niki Afseth (adult)

Clinic (paed.) 306-966-8120
Clinic (adult) 306-655-2208
Emergency 306-655-1000
Office (paed.) 306-966-2922
Office (adult) 306-966-8274
Fax (paed.) 306-966-8640
Fax (adult) 306-966-8694

Clinic Resources

Health Professional	Regina General Hospital (paed.)	Royal University Hospital (paed./adult)
Physiotherapist	YES	YES
Social Worker	YES	YES
Dietitian	YES	YES
Respirologist/Pulmonologist	*	YES
Gastroenterologist	*	*
Psychologist/Psychiatrist	*	*
Pharmacist	*	*
Endocrinologist	*	*

*on referral

Hospital Facilities

Service	Regina General Hospital	Royal University Hospital (paed.)	Royal University Hospital (adult)
Rooming in	YES	YES	N/A
Care by parent	NO	NO	N/A
Hostel service	YES	NO	NO
Educational program - e.g. Tutor	YES	YES	NO
Recreational activities - e.g. Play program	YES	YES	NO
Teen Unit	NO	NO	NO
Adult Unit	YES	NO	YES

Patients colonized with *Burkholderia cepacia* complex are given separate rooms at all hospitals.

All CF patients are prioritized for private rooms at Royal University Hospital.

Drug Plan

Saskatchewan Aids to Independent Living Program (SAIL) provides benefits to assist people with disabilities and certain chronic health conditions through 14 subprograms.

Tel: 306-787-7121
 Web site: <http://www.health.gov.sk.ca/sail>

The **Cystic Fibrosis Program** covers the cost of all drugs listed in the [Saskatchewan Formulary](#) and non-formulary drugs, including supplements and enzymes, to individuals with CF at no charge. Individuals must be referred to the program from a doctor at one of the CF clinics in the province.

Certain drugs may be approved for coverage under the **Exception Drug Status Program (EDS)**. In order to qualify for EDS, an individual must apply, which can be done over the phone. The application includes the individual's name, health services number, the name of the drug, diagnosis relevant to use of the drug, and the prescriber name and phone number. Requests are processed daily on a continuous basis, and notification will be sent in the form of a letter to the patient and prescriber. If the EDS drug is approved as a benefit, then the individual pays for the EDS drug in the same manner as they would for any other benefit drug (the Cystic Fibrosis Program will cover most of these drugs once approved).

Tel: 306-787-8744
 Toll free: 1-800-667-7581
 Web site: <http://www.health.gov.sk.ca/exception-drug-status>

Equipment and Oxygen

The **SAIL Respiratory Equipment Program** assists with the cost of aerosol therapy compressors to eligible residents. The program also covers the cost of spirometers for discharge from hospital after a lung transplant. Loaned equipment includes ventilators, continuous positive airway pressure (CPAP) and bi-level flow generators, tracheostomy humidification compressors, and portable and stationary suctioning equipment.

Feeding pumps and supplies are available from the Saskatchewan Abilities Council and are covered under the **SAIL Children's Enteral Feeding Pump Program**. For more information speak with the CF clinic dietitian, call 306-664-6646, or visit:

<http://www.abilitiescouncil.sk.ca/>

For those who meet the medical criteria, Saskatchewan Health funds home oxygen through the **SAIL Home Oxygen Program**. Saskatchewan Health covers the cost of basic systems, which are supplied by private medical health firms on contract through Saskatchewan Health. Contact information for SAIL is on page 65.

Homecare

Physiotherapy, nursing, and home IV are provided free of charge by the **Provincial Homecare Services Program**. Homemaker services are available in most areas of the province and are funded on a sliding scale fee basis. Contact the CF clinic coordinator, or visit:

<http://www.health.gov.sk.ca/home-care>

Genetic Counselling

Genetic counselling is available in Saskatchewan through the Medical Genetics Clinic. Individuals must be referred through their family doctor. There is also a Genetic Counsellor available at the Royal University Hospital CF clinics for individuals with CF and their families.

Tel: 306-655-1692

Web site: <http://www.medicine.usask.ca/pediatrics/divisions-sections/medical-genetics/>

Newborn Screening

Saskatchewan screens newborns for cystic fibrosis. Please refer to Cystic Fibrosis Canada's [Newborn Screening for Cystic Fibrosis](#) brochure for further information.

Social Support

Contact a local [Cystic Fibrosis Canada chapter](#) or [CF clinic](#) for details of the existing social support network in your area. Cystic Fibrosis Canada chapters are located in [Saskatoon](#) and [Weyburn](#). Please see the back of this [Guide](#) for a listing of all Cystic Fibrosis Canada chapters.

Educational and Vocational Counselling

Workforce Development for Persons with Disabilities Program (WFD-PD), formerly known as Employability Assistance for People with Disabilities (EAPD), provides funding to assist adults with disabilities to prepare for, secure and maintain employment. Various supports are offered, including on-the-job training, employment and work assessments, psycho-educational assessments, job coaching, support for employers and disability-related costs for a wide variety of post-secondary education and training programs.

Tel: 306-798-3105
 Web site: <http://www.aeei.gov.sk.ca/wfd-pd>

Financial assistance may be available to students wishing to attend a post-secondary institute.

Tel: 306-787-2044
 Web site: <http://www.aeei.gov.sk.ca/assistance-for-students-with-permanent-disabilities>

Financial Assistance

Individuals with CF may qualify for financial assistance as persons with disabilities. A clinic social worker will be able to give further information regarding financial assistance options available to persons with CF.

Kinsmen and Kinettes Telemiracle Foundation exists as a special support for individuals living in Saskatchewan who require financial assistance for things such as medical equipment to assist them with daily living. Any individual from Saskatchewan may request funds from the Telemiracle Kinsmen Foundation. Applications may be obtained from any Kinsmen or Kinette club or their provincial office, and must be filled out and returned to the Kinsmen provincial office.

Tel: 306-244-6400
 Web site: <http://www.telemiracle.com>

Advocacy Resources

Cystic Fibrosis Canada is a strong voice and champion for people with cystic fibrosis, their caregivers, and families. The organization works to build awareness of cystic fibrosis and advocates for change to improve the quality of life of people with CF. For more information, contact your regional Adult CF Committee representative (listed at the end of this [Guide](#)) or Cystic Fibrosis Canada.

Saskatchewan Human Rights Commission aims to discourage and eliminate discrimination through investigating complaints of discrimination and promoting and approving equity programs. This includes working with individuals who have visible or invisible physical disabilities. For more information visit <http://www.shrc.gov.sk.ca>, or contact:

Saskatoon Office

Tel: 306-933-5952
 Toll free: 1-800-667-9249

Regina Office

Tel: 306-787-2530
 Toll free: 1-800-667-8577

Saskatchewan Voice of People with Disabilities Inc. works to advocate for the right of people with disabilities within their community, including addressing issues such as employment opportunities and equitable income support.

Tel: 306-569-3111
 Toll free: 1-877-569-3111
 Web site: <http://www.saskvoice.com>

Saskatchewan Children's Advocate ensures the rights, interests and well-being of children and youth in Saskatchewan are respected and valued in the community and in government legislation, policy and practice.

Tel: 1-800-322-7221
 Web site: <http://www.saskcao.ca/>

Transplant Centres and Resources

Transplant Centres

Lung transplant centres are located in Edmonton, Alberta; Vancouver, British Columbia; Winnipeg, Manitoba; Toronto, Ontario; and Montreal, Quebec.

CF candidates for double lung or heart-lung transplantation are referred to the transplant program by their CF clinic director or physician. This referral is based on a number of criteria as determined by the individual's health care providers, and the transplant team.

<p>UNIVERSITY OF ALBERTA HOSPITALS (paed.) Edmonton, Alberta</p> <p>Tel: 780-407-3302 Director: Dr. Jackson Wong Respiratory Nurse: Cathy Schellenberg</p>	<p>UNIVERSITY OF ALBERTA HOSPITALS (adult) Edmonton, Alberta</p> <p>Tel: 780-407-7559 Director: Dr. Dale Lien Transplant Coordinators: Marianne Schafenacker (pre-transplant) Kathy Jackson (post-transplant) Cheryl Salvator (post-transplant)</p>
<p>VANCOUVER GENERAL HOSPITAL (paed./adult) Vancouver, British Columbia</p> <p>Tel: 604-877-2240 Toll free: 1-800-663-6189 Surgeon: Dr. John Yee Transplant Coordinator: Carol Storseth E-mail: BCTS_Webmaster@bcts.hnet.bc.ca Web site: http://www.transplant.bc.ca/index.asp</p>	<p>HEALTH SCIENCES CENTER (paed./adult) Winnipeg, Manitoba</p> <p>Tel: 204-787-1521 Director: Dr. H. W. Unruh Transplant Coordinator: Clare Rubin</p>
<p>THE HOSPITAL FOR SICK CHILDREN (paed.) Toronto, Ontario</p> <p>Tel: 416-813-2233 Medical Director: Dr. M. Solomon Transplant Coordinator: Alison Drabble Web site: http://www.sickkids.ca/</p>	<p>TORONTO GENERAL HOSPITAL (adult) Toronto, Ontario</p> <p>Tel: 416-340-4800 x 3807 Program Director: Dr. S. Keshavjee Medical Director: Dr. L. Singer Assessment Coordinator: Cathy Whytehead Transplant Coordinators: Josie Dorosz Debbie Zogalo Web site: http://www.uhn.ca/focus_of_care/mot/Lung/index.asp</p>
<p>CENTRE HOSPITALIER DE L'UNIVERSITÉ DE MONTRÉAL (paed./adult) Montreal, Quebec</p> <p>Tel: 514-890-8000 Directors: Dr. C. Poirier Dr. P. Ferraro Web site: http://www.chumtl.qc.ca</p>	

The following information provides resources for individuals seeking lung transplants, and their families, that may help with the financial costs associated with having to relocate for a transplant and/or other transplant-related costs. Programs vary significantly in the type of support provided; whether money is delivered up front or reimbursed; and the application process and documentation required.

Some provinces provide financial support for living organ donors whose organs benefit a resident of their province. For information on living organ donation and support resources, contact the relevant provincial health department.

Canada-wide Resources

Social assistance programs

Some provincial governments provide additional financial support to individuals seeking medical treatment while on social assistance. Contact your provincial government or CF clinic social worker for more information or review the relevant provincial section in this *Guide*.

Canadian Lung Association may provide financial support to individuals. The amount of support and application process varies by province, and requests are evaluated on a case-by-case basis.

Toll free: 1-888-566-5864
Web site: <http://www.lung.ca>

Canadian Association of Transplantation (CAT) has built a caring and professional foundation for the transplantation process in Canada. CAT plays a critical role in the development of guidelines and safety issues involving the distribution of organs and tissues.

For a list of provincial donor programs, visit:
http://www.transplant.ca/cancon_donorprog.htm

For a list of provincial transplant programs, visit:
http://www.transplant.ca/cancon_transprogram.htm

Hope Air assists with the cost of air transportation for individuals needing to travel for medical treatment, including transplant-related appointments. Qualifying individuals must demonstrate financial need, and have a scheduled medical appointment.

Toll free: 1-877-346-4673
E-mail: mail@hopeair.org
Web site: <http://www.hopeair.org>

David Foster Foundation is a last resort payer to help those who have no other means of financial support to cover the non-medical expenses that arise when a child (18 and younger) needs a transplant, including out-of-province travel and accommodations.

Tel: 250-475-1223
Toll free: 1-877-777-7675
E-mail: info@davidfosterfoundation.com
Web site: <http://www.davidfosterfoundation.org>

Local Service Clubs

Most communities have local service groups, which often help individuals and families in their community facing personal hardship. These clubs may help individuals with CF and their families with their fundraising activities or provide direct assistance. Check your local directory to find service clubs in your area, and visit the following Web sites.

Kin Canada: <http://www.kincanada.ca>
Lions Clubs International: <http://www.lionsclubs.org>
Rotary International: <http://www.rotary.org>
Civitan International: <http://www.civitan.org>

Personal Fundraising

Many individuals seeking transplants fundraise to help defray transplant-related costs such as accommodation or travel expenses.

When raising funds, it is important to plan and explain how the money raised will be used. It may be helpful to set-up a separate bank account to hold the funds. One option is to open a Trust Fund Account, which sets out how the funds can be used, and provides some confidence to donors that that money will be used for the designated purpose. Most major banks can set-up trust accounts. To set-up an account, decide who will be the signing officers and prepare a description of the purpose for the account. Trust accounts are subject to regular banking fees. It is suggested that you speak to an accountant or lawyer before setting up a trust account.

Alberta

University of Alberta Hospital Outpatient Residence is attached to the University Hospital in Edmonton and is available to transplant patients. The transplant coordinator or social worker can provide more information.

Tel: 780-407-6593

Variety - The Children's Charity of Alberta has programs to assist children with special needs who require financial assistance. To apply, the recipient must be under 19 years of age and have a disability. Variety will not consider requests for services covered by any other provincial program. Contact Variety Alberta or your social worker for more information.

Tel: 403-228-6168
Web site: <http://www.varietyalberta.ca/>

British Columbia

Variety - The Children's Charity of British Columbia has programs to assist children with special needs who require financial assistance. To apply, the recipient must be under 19 years of age and have a disability. Variety will not consider requests for services covered by any other provincial program. Contact Variety B.C. or your social worker for more information.

Tel: 604-268-3893
 Toll free: 1-800-381-2040
 E-mail: heart.fund@variety.bc.ca

Travel Assistance Program (TAP) helps alleviate some of the transportation costs for eligible B.C. residents who must travel within the province for medical services not available in their own community. TAP is a corporate partnership between the Ministry of Health Services and private transportation carriers, who discount or waive their regular fees. TAP does not provide direct financial assistance to patients for travel costs, and does not include accommodation, fuel or local transportation expenses.

Tel: 250-952-1742
 Toll free: 1-800-465-4911
 E-mail: HLTH.RuralHealth@gov.bc.ca
 Web site: <http://www.health.gov.bc.ca/tapbc>

Health Connections is a regional travel assistance program that offers subsidized transportation options to help defray costs for rural residents who must travel to medical care outside their home communities.

http://www.busonline.ca/health_connections/

Medical Travel Accommodations Listing

The B.C. government maintains a list of businesses who offer accommodation at discounted rates to patients and their families required to travel for medical treatments. To book at the reduced rate, individuals should contact the hotel they wish to stay at, and request the medical rate when booking, and be prepared to provide documentation such as a doctor's note.

<http://www.pss.gov.bc.ca/csa/categories/accommodation/medical/search/>

For people at Vancouver General Hospital, the Shaughnessy Inn offers nightly and monthly accommodation close by for a reasonable price.

Tel: 604-736-5511

Manitoba

Thoracic Surgery Trust Fund supports patient needs, including: lodging for out-of-town patients and their families at Lennox Bell Lodge; travel expenses to and from the centre, and in-hospital costs. Contact the Winnipeg lung transplant centre coordinator for more information.

Lennox Bell Lodge is a unique hostel service, which provides affordable lodging for out-of-town residents who come to the Health Sciences Centre in Winnipeg and CancerCare Manitoba for outpatient treatment. Family and friends of inpatients or guests receiving outpatient treatment are also welcome.

Tel: 204-774-6511
 Web site: <http://www.hsc.mb.ca/lennox/>

Lions Foundation of Manitoba and Northwestern Ontario assists recipients in Manitoba and Northwestern Ontario with the non-medical costs (i.e. travel, accommodations, and special equipment) that are not covered by government funding. It also has an apartment in Winnipeg available to individuals who must travel to receive treatment.

Tel: 204-788-8507
 E-mail: ifmnoi@mts.net
 Web site: <http://www.eyebankmanitoba.com>

Newfoundland and Labrador

Medical Transportation Assistance Program provides financial assistance to residents of the province who must travel for insured services not available within their place of residency and/or province. Eligibility may be affected by other social assistance programs.

E-mail: francinasweetapple@gov.nl.ca
 Web site: <http://www.health.gov.nl.ca/health/mcp/travelassistance.html>

Nova Scotia

Out of Province Travel and Accommodation Assistance Policy program provides financial support for travel and accommodation for Nova Scotia residents who have to travel out-of-province to receive medical treatment. The program will reimburse \$125 per night for accommodation (not exceeding \$1,500 per month), and \$1,000 toward one round trip plane, bus, or train ticket (maximum 12 trips per year).

Tel: 902-424-7499
 Toll free: 1-877-447-5476
 Web site: <http://www.gov.ns.ca/health/OOP/default.asp>

Ontario

Transplant Patient Expense Reimbursement Program (TPER) provides financial support for Ontario residents who must temporarily relocate in the vicinity of the transplant hospital within the province to receive heart, heart-lung, or lung transplants. The program is funded by the Ontario Ministry of Health and Long-Term Care, and administered by the Trillium Gift of Life Network. TPER will reimburse relocation accommodation expenses of \$650 per month to a maximum of \$7,800 per year to individuals waiting for transplant, and for two months post-transplant. TPER eligibility may be affected by other social assistance programs. Contact the transplant coordinator or social worker for more information about the program.

<http://www.giftoflife.on.ca/>

Lions Foundation of Manitoba and Northwestern Ontario

[See Manitoba section, page 73.]

The Jennifer Ashleigh Foundation seeks to improve the quality of life for chronically and seriously ill children and their families, who are residents of Ontario and demonstrate financial need. The Foundation considers requests for the benefit of a child up to the age of 21 years of age. It will consider requests for emergency financial relief, medical treatment not covered by OHIP, and parental relief.

Tel: 905-852-1799
 E-mail: generalmail@jenash.org
 Web site: <http://www.jenniferashleigh.org/>

Toronto Lung Transplant Civitan Club provides direct assistance and support to transplant patients at Toronto General Hospital. Its mandate is to help with any transplant-related costs, including accommodation and meals. Requests are evaluated based on individual need and available funds. Civitan also sells medical devices, such as spirometers, at a reduced price.

Tel: 905-639-5927
 E-mail: lungs@torontolungtransplantclub.org
 Web site: <http://torontolungtransplantclub.org/>

Program for Reimbursing Expenses of Living Organ Donors (PRELOD) is a last resort program which provides financial support to reduce the financial burden associated with living organ donation. The recipient of the organ must be an Ontario resident covered by OHIP.

<http://www.giftoflife.on.ca/assets/pdfs/PREPublicFAQsV1.pdf>

Prince Edward Island

Out of Province Travel and Accommodation Assistance for Transplant program provides financial support for travel and accommodation for P.E.I. residents who have to travel outside of the Maritime Provinces to receive transplants. The program will reimburse \$1,000 per month for accommodation, and the cost of one round trip plane, bus, or train ticket every six months (not exceeding \$1,500).

Tel: 902-368-6516

Quebec

Régie de l'assurance maladie du Québec

If it is medically necessary for an individual to relocate out-of-province for a lung transplant, assistance may be available through the Quebec provincial government. Contact the *Régie de l'assurance maladie du Québec* for more information.

Québec: 418-646-4636
 Montréal: 514-864-3411
 Web site: <http://www.ramq.gouv.qc.ca>

AirMédic is an emergency transportation service. Individuals waiting for transplant who live in remote areas or who because of their circumstances cannot relocate to Montreal while waiting may be eligible to use *AirMédic* for air transportation to the hospital.

Tel: 418-673-3838
 Toll free: 1-866-673-3838
 E-mail: info@airmedic.net
 Web site: <http://www.airmedicquebec.com>

La Fondation Diane Hébert provides advocacy and companionship services, such as individual and group meetings, for transplant beneficiaries. The organization has residences for out-of-town patients who must temporarily stay near a transplant centre for preliminary or post-operative examinations.

Tel: 514-970-1113
 E-mail: infos@fondationdianehebert.org
 Web site: <http://fondationdianehebert.org>

Fondation des greffés pulmonaires du Québec raises money for an emergency fund managed by the lung transplant program social worker at the Notre-Dame Hospital in Montreal. Assistance is provided to help individuals waiting for transplant or post-transplant pay for out-of-pocket expenses, such as, accommodation at *Maison des greffés*, meals, or transportation. It also lends out equipment (e.g. spirometers). Contact the organization or the social worker at the Notre-Dame Hospital for more information.

Tel: 450-667-2443
 E-mail: info@fgpq.org
 Web site: <http://www.fgpq.org/>

Lina Cyr Foundation, Maison des greffés du Québec offers transplant patients and their families, who reside outside of Montreal, an affordable place to stay when they come to Montreal for treatment. Each bedroom has internet access, meals are included, and residents have access to an exercise room and other amenities. Free transportation is provided to the hospital. No medical staff on site.

Tel: 514-527-8661
E-mail: fondation.linacyr@videotron.ca
Web site: <http://www.maisondesgreffes.com>

Saskatchewan

The Kinsmen Telemiracle Foundation supports, promotes, and fosters programs that benefit people with special needs in Saskatchewan. The Foundation provides financial assistance to Saskatchewan residents to facilitate improved quality of life and independence. It also assists with in and out-of-province travel expenses for individuals receiving medical treatment, assessments, and organ transplants.

Tel: 306-244-6400
Toll free: 1-877-777-8979
E-mail: telemiracle@sasktel.net
Web site: <http://www.telemiracle.com>

Contacts

Adult Cystic Fibrosis Committee (ACFC)

<p>Chair NATHAN FISH London, Ontario E-mail: acfcchair@cysticfibrosis.ca</p>	<p>Quebec Vice-Regional Representative TBA Montreal, Quebec E-mail: acfcquebecvicerep@cysticfibrosis.ca</p>
<p>Vice-Chair KELLY SHEPPARD Carbonear, Newfoundland & Labrador E-mail: acfcvicechair@cysticfibrosis.ca</p>	<p>Western Regional Representative MEGAN PARKER Calgary, Alberta E-mail: acfcwestrep@cysticfibrosis.ca</p>
<p>Atlantic Regional Representative JAMIE CHAFE Glenwood, Newfoundland & Labrador E-mail: acfcatlanticrep@cysticfibrosis.ca</p>	<p>Western Vice-Regional Representative TRACEY FISHER Calgary, Alberta E-mail: acfcwestvicerep@cysticfibrosis.ca</p>
<p>Atlantic Vice-Regional Representative JESSICA CARVER New Germany, Nova Scotia E-mail: acfcatlanticvicerep@cysticfibrosis.ca</p>	<p>Editor, Circle of Friends CARLY STAGG Airdrie, Alberta E-mail: acfceditor@cysticfibrosis.ca</p>
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<p>Ontario Vice-Regional Representative DEBRA MATTSON Port Perry, Ontario E-mail: acfcontariovicerep@cysticfibrosis.ca</p>	<p>M/SAC Representative DR. HARVEY RABIN Calgary, Alberta E-mail: acfcmsacrep@cysticfibrosis.ca</p>
<p>Quebec Regional Representative PATRICK BROTHERS Laval, Quebec E-mail: acfcquebecrep@cysticfibrosis.ca</p>	

Adult Cystic Fibrosis Committee of Quebec (ACFCQ)

Office Tel: 514-288-3157 Toll free: 1-800-315-3157 Web site: www.cpafk.qc.ca E-mail: cpafk@videotron.ca	President of the Board of Directors and Director PIERRE-ALEXANDRE TREMBLAY E-mail: president@cpafk.qc.ca
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Secretary, Deputy Delegate to Cystic Fibrosis Quebec and Representative, Laval-Laurentides-Lanaudière ÉLISE BOUCHARD E-mail: laval_laurentides_lanaudiere@cpafk.qc.ca	Special Advisor to the Executive Committee and Board of Directors and Deputy Delegate to the ACFC PATRICK BROTHERS E-mail: brotherp@videotron.ca
Special Advisor to the Executive Committee RICHARD LEOEUF-MCGREGOR E-mail: richardleboeuf2000@yahoo.fr	Special Advisor to the Executive Committee and Representative, Bas-Saint-Laurent-Gaspésie-Îles-de-la-Madeleine FRÉDÉRIC VILLENEUVE
Special Advisor to the Board of Directors BERNARD CYR	Special Advisor to the Board of Directors CLAIRE BOULERICE
Special Advisor to the Board of Directors VALÉRIE MOUTON	Professional Advisor and Honorary Member JOSÉE LESSARD E-mail: jlessard.chus@ssss.gouv.qc.ca
Treasurer ANNIE DUBREUIL E-mail: tresorerie@cpafk.qc.ca	Assistant Director ANDRÉE DELISLE
President of the Board of Directors of Cystic Fibrosis Quebec and Honorary Member JULIE SAUCIER E-mail: Julie.St-Pierre@pha.ulaval.ca	Director General and Editor SVB LAVAL DE LAUNIÈRE E-mail: dg@cpafk.qc.ca

Cystic Fibrosis Canada Chapters

Alberta

<p>Calgary & Southern Alberta President: Jeanette Demers-Weir Office Coordinator: Teri Lang Tel: 403-266-5295 Web site: www.cfcalgary.ca E-mail: info@cfcalgary.ca</p>	<p>Edmonton & Northern Alberta Chapter Coordinator: Katherine Lauzon Tel: 780-466-2265 Web site: www.cfedmonton.ca E-mail: ecfs@telus.net</p>
<p>Central Alberta President: Brandi French Tel: 403-347-5075 E-mail: cfccentralalberta@gmail.com</p>	

British Columbia

<p>Campbell River President: Jo-Ann Wallis Tel: 250-932-3916 Web site: www.crcf.ca E-mail: mustangsally45@hotmail.com</p>	<p>Powell River Satellite Contact: Lorne Villani Tel: 604-485-9337 E-mail: lorvilla@shaw.ca</p>
<p>Kamloops President: John Bowers Tel: 250-314-1606 E-mail: catchnrelease@shaw.ca</p>	<p>Prince George President: Lesley Girard Tel: 250-561-2129 E-mail: mlgirard@hotmail.com</p>
<p>Nanaimo President: Debra Tuck Tel: 250-753-1597 E-mail: dtuck-is@shaw.ca</p>	<p>Vancouver/Lower Mainland Director: Martina Meckova Tel: 604-436-1158 Web site: www.cfvancouver.ca E-mail: director@cfvancouver.ca</p>
<p>Okanagan Valley President: Jody Birnie Tel: 250-869-1407 E-mail: jdbirnie@shaw.ca</p>	<p>Victoria Co-Presidents: Heather and Dave Strange Tel: 250-642-6906 Web site: www.cysticfibrosisvictoria.ca E-mail: victoriacfchapter@shaw.ca</p>

Manitoba

<p>Winnipeg President: Darcy Hodgins Tel: 204-269-5096 E-mail: darcyhodgins@mts.net</p>	
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New Brunswick

<p>Fredericton and Northwest Valley President: TBA Tel: 1-800-378-2233 E-mail: info@cysticfibrosis.ca</p>	<p>Saint John President: Betty Melanson Tel: 506-738-0914 E-mail: meldrap@nbnet.nb.ca</p>
<p>Moncton President: Vivian Smith Tel: 506-852-9341 E-mail: smithviv@nb.sympatico.ca</p>	

Newfoundland and Labrador

<p>Eastern Newfoundland President: Betty Sheppard Tel: 709-368-4475 Web site: http://www.envision.ca/webs/ccffnewfoundland E-mail: sheppardbetty@hotmail.com</p>	<p>West Coast Newfoundland & Labrador Satellite President: Geraldine Murphy Brown Tel: 709-282-3514</p>
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Nova Scotia

<p>Cape Breton Island President: Bob Fortier Tel: 902-539-5246 E-mail: bob.fortier@gmail.com</p>	<p>South Western Nova President: Dorothy Vallillee Tel: 902-742-2304 E-mail: dotvallillee@eastlink.ca</p>
<p>Scotia President: Ross Drake Development Coordinator: Pamela Barnes Tel: 902-425-2462 E-mail: pamela@cfnovascotia.ca</p>	

Ontario

<p>Cornwall President: Kim Baird Tel: 613-933-5851 E-mail: bairdjk@cogeco.ca</p>	<p>North Bay President: Mike Croghan Tel: 705-474-7487 E-mail: mcroghan@cogeco.ca</p>
<p>Durham Region President: Mitch LePage Tel: 905-666-2116 E-mail: mitch.lepage@rogers.com</p>	<p>Ottawa President: André Chartrand Tel: 613-230-6643 E-mail: andy.chartrand@rogers.com</p>

Ontario continued

<p>Essex-Kent (formerly Windsor) Development Coordinator: Chantelle Foreman Tel: 519-252-2850 E-mail: windsorcysticfibrosis@cogeco.ca</p>	<p>Peel & District President: Frank Aucoin Chapter Manager/Fundraising Coordinator: Dolores Adams Tel: 905-450-1882 Web site: www.ccffpeel.org E-mail: admin@cfpeel.org</p>
<p>Hamilton President: Karen Gliddon-Napper Tel: 519-717-8898 E-mail: kgcf@sympatico.ca</p>	<p>Peterborough President: Pam Grady Tel: 705-652-1525 E-mail: pgrady@prhc.on.ca</p>
<p>Huron-Oxford-Perth (H.O.P.E.) President: Donna Mitchell Tel: 519-291-5837 E-mail: dmitchell@cyg.net</p>	<p>Sarnia-Lambton President: Paul Croft Tel: 519-869-4356 Web site: www.cysticfibrosissarnia.com E-mail: info@cysticfibrosissarnia.com</p>
<p>Kingston - Brockville Subchapter President: Caroline Rigotto Tel: 613-345-3928 E-mail: crigutto@sympatico.ca</p>	<p>Sault Ste. Marie President: Marilyn King Tel: 705-942-0273 E-mail: brasonking@shaw.ca</p>
<p>Kitchener-Waterloo District President: Katie Schulz Coordinator: Sue House-Willis Tel: 519-772-2300 E-mail: kwdcfc@golden.net</p>	<p>Sudbury President: TBA Tel: 1-800-378-2233 E-mail: info@cysticfibrosis.ca</p>
<p>London President: Bea Crowley Tel: 519-615-1355 Web site: www.cysticfibrosislondon.ca E-mail: info@cysticfibrosislondon.ca</p>	<p>Thunder Bay President: Gloria Houghton Tel: 807-766-9710 E-mail: glowar@tbaytel.net</p>
<p>Niagara President: Mary-Ellen Scotney Tel: 289-296-7941 E-mail: mscotney2@cogeco.ca</p>	<p>Toronto & District President: Ron Anderson Tel: 416-932-3900 Web site: www.cfftoronto.ca E-mail: toronto@cysticfibrosis.ca</p>

Prince Edward Island

<p>Prince Edward Island President: Melvin Jay Tel: 902-676-2986 E-mail: mijay676@hotmail.com</p>	
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Quebec

<p>Cystic Fibrosis Quebec Tel: 514-877-6161 Toll free: 1-800-363-7711 Web site: http://www.aqfk.qc.ca E-mail: info@fibrosekystiquequebec.ca</p>	<p>Lac-Saint-Jean President: Monique Gobeil Tel: 418-668-7681 E-mail: monique.gobeil@cgocable.ca</p>
<p>Bas Saint-Laurent/Gaspésie Treasurer: Nathalie Arsenault Tel: 418-723-7560 E-mail: nathetfred@cgocable.ca</p>	<p>Mauricie-Centre du Québec President: Lisette Tremblay Tel/Fax: 819-693-6168 E-mail: sourislisette@hotmail.com</p>
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Other Publications

- [*Cystic Fibrosis in Canada*](#)
- [*Newborn Screening for Cystic Fibrosis*](#)
- [*Carrier Testing for Cystic Fibrosis*](#)
- [*Infection Control and Cystic Fibrosis*](#)
- [*Your Child and Cystic Fibrosis*](#)
- [*Education and Cystic Fibrosis: Information for Teachers and Professors*](#)
- [*Cystic Fibrosis and Lung Transplantation*](#)
- [*Sexuality and Cystic Fibrosis: Information for Adolescents*](#)
- [*Sexuality, Fertility and Cystic Fibrosis: Information for Adults*](#)
- [*When a Parent has CF: Explaining your Illness to Your Child*](#)
- [*Clinical Trials: Information and Options for People with Cystic Fibrosis*](#)
- [*Disability Tax Credit and Cystic Fibrosis*](#)
- [*Registered Disability Savings Plan and Cystic Fibrosis*](#)
- [*Adult Cystic Fibrosis Committee*](#)
- [*Summer Tips for CF Care*](#)
- [*Travelling with CF*](#)
- [*Candid Facts*](#)
- [*Circle of Friends*](#)
- [*Canadian Patient Data Registry*](#)
- [*Hope Through Progress: Clinical and Scientific Research Programs*](#)
- [*Annual Report*](#)

Canada continues to be a world leader in cystic fibrosis research and care. Thanks to the progress we have made, half of all Canadians with cystic fibrosis are expected to live into their 40s and beyond. While this is remarkable progress, many young Canadians with CF die far too soon, and much work remains to be done. Support from all Canadians will enable us to expand our investment in important programs for people with cystic fibrosis.

Cystic Fibrosis Canada

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