

# CYSTIC FIBROSIS RESOURCE GUIDE 2019 - 2020



A GUIDE OF RESOURCES AND DISABILITY SUPPORTS  
FOR THE CYSTIC FIBROSIS COMMUNITY IN CANADA

*Updated as of: December 13th, 2019*



Cystic Fibrosis  
Fibrose kystique  
Canada

# CYSTIC FIBROSIS

Cystic fibrosis (CF) is a rare genetic multi-system disease that mainly affects the respiratory and digestive system, but can also affect the sinuses, liver, pancreas and reproductive organs. The organ(s) affected and degree of severity differs from person to person. However, the effects are most devastating in the lungs due to a build-up of thick mucous which causes severe respiratory problems. Additionally, there has been growing attention to the emotional wellness, and overall mental health in the CF population and among their caregivers, particularly in the areas of anxiety and depression. CF is a progressive disease affecting over 4,300 Canadians<sup>1</sup>. Currently, there is no cure.

## CYSTIC FIBROSIS CANADA

Cystic Fibrosis Canada is a national not-for-profit health charity established in 1960, with 50 volunteer chapters across Canada. Our mission is to end cystic fibrosis (CF) by helping all people living with CF, principally by funding targeted world-class research, supporting and advocating for high-quality individualized CF care, and raising and allocating funds for these purposes. Additionally, Cystic Fibrosis Canada provides clinic incentive grants to help support the 42 CF clinics in Canada, it produces educational materials and offers an information requests and referrals service for the CF community and general public. We are committed to continue and work towards our vision of a world without cystic fibrosis.

### CYSTIC FIBROSIS CANADA

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Website: [www.cysticfibrosis.ca](http://www.cysticfibrosis.ca)

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# INTRODUCTION

The services and resources that are available to people with cystic fibrosis (CF) and their caregivers in Canada vary between provinces, and it can be challenging to find or identify the services and resources you may need.

Cystic Fibrosis Canada provides the *Cystic Fibrosis Resource Guide: a guide of resources and disability supports for the cystic fibrosis community in Canada*, including CF clinics and Cystic Fibrosis Canada chapters, as a source of information for Canadians with CF, their friends, families and/or caregivers.

## THE CYSTIC FIBROSIS RESOURCE GUIDE IS INTENDED TO:

- outline services, programs, and resources available in each province and across the country;
- provide guidance for the CF community to navigate local and nation-wide resources;
- assist persons with CF and their families who may be travelling or moving between provinces; and,
- identify areas for which advocacy is needed to improve access to services and resources for persons with cystic fibrosis.

## THE CYSTIC FIBROSIS RESOURCE GUIDE IS COMPRISED OF FIVE PARTS:

- section one outlines information on services and resources provided by the federal government and national agencies
- section two outlines clinical and community services, programs, and resources offered on a provincial or regional basis
- section three includes some tips and best practices for CF management
- section four lists contact information for Cystic Fibrosis Canada chapters
- Section five provides links to a number of other resources relevant to cystic fibrosis.

Within each provincial section, the following categories are covered: clinic contact, resources and facilities information; drug and medical coverage; nutritional supplements; financial assistance; education and employment; mental health and emotional wellness; medical equipment, supplies and oxygen; home care; social supports; advocacy; genetic counselling and testing; newborn screening; and transplant centres. The services and programs detailed within the provincial sections are in addition to all the resources listed within the nation-wide section of the guide.

This document is updated on a bi-yearly basis; however, given that the programs outlined in the *Cystic Fibrosis Resource Guide* are managed by external organizations or government, 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 *Cystic Fibrosis Resource Guide*, or to provide further information. Inquiries can be directed to Cystic Fibrosis Canada at:

**Telephone:** 416-485-9149  
**Toll free:** 1-800-378-2233  
**E-mail:** [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca)

## CYSTIC FIBROSIS CANADA RESOURCES

### INFORMATION REQUESTS AND REFERRALS SERVICE

Cystic Fibrosis Canada provides an information request and referral service to help the CF community navigate government and community-based resources. This bilingual service assists with inquiries typically related to the following topics: CF diagnosis, CF facts, CF health, clinical, education, employment, finances, government relations and advocacy, global affairs, and research. You can contact Eunice, Coordinator, Community Relations and Resources, with any queries pertaining to resources and disability supports at [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or by calling Cystic Fibrosis Canada at 1-800-378-2233 ext. 403.

### ADULT CYSTIC FIBROSIS ADVISORY COMMITTEE (ACFAC)

The Adult Cystic Fibrosis Advisory Committee is a standing committee of Cystic Fibrosis Canada. The committee provides perspective and advice on CF-related issues, and advocates for public policies and programs to help people with cystic fibrosis. Members work to foster and support an engaged and knowledgeable CF community. Currently, the committee is in the works of developing resources such as a guide for parents living with CF, a fertility and family planning educational webinar series, and a guide for people transitioning from paediatric to adult clinics, amongst other initiatives. You can contact Megan, Chair, ACFAC, with any questions about the work that the committee is doing, at [meganmparker@hotmail.com](mailto:meganmparker@hotmail.com).

### NATIONAL ADVOCACY PROGRAM

Cystic Fibrosis Canada has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. With over 100 volunteers across the country, Cystic Fibrosis Canada strives to influence decision-makers and ensure the insight, experience and expertise of patients with cystic fibrosis, as well as that of their friends and families, is considered. If you are interested in volunteering or want to get in touch about government relations and advocacy priorities, you can contact our team at [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or by calling:

Eric, Associate, Government Relations and Advocacy: 1-800-378-2233 ext. 305  
Kim, Director, Government and Community Relations: 1-800-378-2233 ext. 297

## CYSTIC FIBROSIS CANADA

A number of resources are available on the Cystic Fibrosis Canada website. Have a look through our virtual education programs or our resources page if you have not already.

## CYSTIC FIBROSIS CANADA BLOG

The Cystic Fibrosis Canada Blog is an option for keeping up to date with information on subjects such as advocacy, CF care, news, research, spotlights, stories, and messages from the CEO.

## ANNUAL DATA REPORT

Cystic Fibrosis Canada publishes a data report annually which includes CF facts from the Canadian Cystic Fibrosis Registry.

# 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. For more information, please visit: [Canada's healthcare system](#).

## 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. Additionally, Health Canada is responsible for approving drugs, natural health products and medical devices for use in Canada, as well as regulating and monitoring clinical trials.

## FEDERAL GOVERNMENT DRUG BENEFIT PROGRAMS

The federal government provides drug coverage for [First Nations and Inuit](#), [inmates in federal penitentiaries](#), [members of the military](#), [members of the RCMP](#), and [veterans](#). To determine your eligibility, please visit: [Federal Public Drug Benefit Programs](#).

## 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.

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, which has its own review board by INESSS). For more information, please visit: [Procedure and Submission Guidelines for the CADTH Common Drug Review](#)

## NATIONAL INSTITUTE OF EXCELLENCE IN HEALTH AND SOCIAL SERVICES (INESSS)

Similar to CADTH, [INESSS](#) conducts reviews of the effectiveness of drugs (both clinical and cost), and provides recommendations regarding formulary listing to the publicly funded provincial drug plan in Quebec.

## CLINICAL TRIALS

To learn about and/or find a clinical trial, please visit [Clinical Trials Network](#), and view our [Clinical Trials Road Map](#). To participate, discuss your eligibility with your CF clinic team.

To access a searchable database with information about active studies currently recruiting world-wide, please visit [ClinicalTrials.gov](#).

## CANADA BENEFITS

[Canada Benefits](#) is a Government of Canada website that connects individuals to provincial and federal government benefits (including tax benefits, scholarships, bursaries and more). For more information, please use the [Canada Benefits Finder](#).

## 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 online. Some of the Service Canada programs that are relevant to the CF community include:

[Canada Pension Plan \(CPP\) Disability Benefits/Quebec Pension Plan \(QPP\) Disability Benefits](#) 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 to receive benefits.

[Child Disability Benefit \(CDB\)](#) is available to eligible families with low or modest incomes, with children under age 18 who qualify for the disability amount. A specific tax-free monthly benefit payment is calculated based on number of eligible children, family net income and marital status.

[Employment Insurance \(EI\) 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).

**Employment Insurance (EI) Regular Benefits** may be paid to people who are unemployed due to no fault of their own (i.e. let go due to shortage of work, seasonal or mass lay-offs, etc.). Eligibility criterion includes a requirement that individuals be available, willing and able to work but unable to find a job. Claims must be made within 4 weeks of the last work day.

**Employment Insurance (EI) Sickness Benefits** may be paid to people unable to work due to sickness, injury, or quarantine. Temporary financial assistance may be provided to eligible unemployed workers for up to a maximum of 15 weeks.

**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.

## 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 **General Income Tax and Benefit Guide** or call 1-800-959-8281.

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. For recommendations on how to apply for these benefits, **please view Appendix E**. The available tax credits, deductions and benefits include:

**Canada Caregiver Credit (CCC)**, effective as of 2017, combines the following three previous credits: the caregiver credit, the family caregiver credit and the credit for infirm dependants age 18 or older. The CCC may be claimed by an individual who supports a spouse or common-law partner, or a dependant with a physical or mental impairment.

**Canada Child Benefit (CCB)**, a tax-free monthly payment made to eligible families to help them with the cost of raising children under age 18. Marital status is considered.

**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”.

**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 developed a Disability Tax Credit and Cystic Fibrosis brochure that you can view **here**.

**Goods and services tax/harmonized sales tax (GST/HST) exemptions** are available to qualifying persons with disabilities, and include hospital parking, home-delivered meals, specially equipped motor vehicles, home care services and medical devices.



**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 **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.

**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 held an RDSP and CF webinar that you can view [here](#).

**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.

More information about programs or credits available to persons with disabilities and their families can be found at [Canada Revenue Agency \(Disability-Related Information\)](#).

## 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, contact:

**Toll free:** 1-866-811-0055  
**E-mail:** [droits-rights@pch.gc.ca](mailto:droits-rights@pch.gc.ca)

**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** at:

**Toll free:** 1-888-214-1090  
**E-mail:** [info.com@chrc-ccdp.gc.ca](mailto:info.com@chrc-ccdp.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 *Cystic Fibrosis Resource 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 *Cystic Fibrosis Resource Guide*.

## ADVOCACY ORGANIZATIONS AND SERVICES

**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.

**E-mail:** [info@ala.ca](mailto:info@ala.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.

**Telephone:** 613-236-9877  
**E-mail:** [info@ccsd.ca](mailto:info@ccsd.ca)

**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.

**Telephone:** 204-947-0303  
**E-mail:** [ccd@ccdonline.ca](mailto:ccd@ccdonline.ca)

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

**Telephone:** 416-425-3463 (Canada Head Office)  
**Toll free:** 1-800-263-3463

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

**Telephone:** 613-380-8065  
**Toll free:** 1-877-670-1256  
**E-mail:** [info@neads.ca](mailto:info@neads.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.

**Telephone:** 613-236-6636  
**Toll free:** 1-888-669-4001  
**E-mail:** [reach@reach.ca](mailto:reach@reach.ca)

## FINANCIAL AND SOCIAL SUPPORT SERVICES

**Children's Wish Foundation of Canada** grants wishes to Canadian children between the ages of 3 and 17 that have a life-threatening illness. Their newly expanded reach includes children diagnosed with a genetic condition.

**Telephone:** 905-839-8882  
**Toll free:** 1-800-700-4437  
**E-mail:** [grantawish@childrenswish.ca](mailto:grantawish@childrenswish.ca)

**David Foster Foundation** helps families of Canadian children who have no other means of financial support to cover the non-medical expenses that arise when a child needs a transplant, including travel (if more than 100km) and accommodations.

**Telephone:** 250-475-1223 (Victoria, Head Office)  
**Toll free:** 1-877-777-7675

**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.

**Telephone:** 416-222-6335  
**Toll free:** 1-877-346-HOPE (4673)

**Julia Lyons Foundation** provides financial assistance, specifically to those in the CF community, to help alleviate the costly burden cystic fibrosis can be due to continuous medical treatment, any monitoring that may be required, lung transplant-related expenses and other expensive procedures.

**Telephone:** 647-955-9733  
**E-mail:** [info@juliaalyonsfoundation.com](mailto:info@juliaalyonsfoundation.com)

**Kids Up Front** provides art, cultural, sport or recreational event tickets, which would otherwise go unused, to children and families in need.

**Telephone:** *different local phone numbers per chapter, please visit their website*  
**E-mail:** [info@kidsupfront.com](mailto:info@kidsupfront.com)

[Make a Wish Foundation Canada](#) aims to grant wishes for children with critical illnesses. They work to deliver life-changing experiences to children across Canada.

**Telephone:** 416-224-9474  
**Toll free:** 1-888-822-WISH (9474)  
**E-mail:** [nationaloffice@makeawish.ca](mailto:nationaloffice@makeawish.ca)

[Starlight Children's Foundation](#) works to better the lives of children with serious illnesses and their families. It provides In-Hospital and Out-of-Hospital programs for children and families to enjoy 'distractive' entertainment and more.

**Toll free:** 1-888-782-7947  
**E-mail:** [info@starlightcanada.org](mailto:info@starlightcanada.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 websites:

[Kin Canada](#)

[Lions Clubs International](#)

[Rotary International](#)

[Civitan International](#)

## EDUCATIONAL AWARDS – SCHOLARSHIPS AND BURSARIES

Most post-secondary institutions have on-campus organizations or departments to assist students with disabilities who can benefit from financial assistance. Prior to settling on a school, we encourage students with CF to investigate their potential campus' services. Most application deadlines occur as early as March, so research and apply 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 websites that are dedicated to listing awards from all areas for easy searching and access. The following are financial assistance opportunities for people seeking higher education.

**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. To further inquire, contact [your provincial office](#).

For more information about student grants and loans, please visit: [Student Financial Assistance](#)

[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.

**Toll free:** 800-742-5546  
**E-mail:** [kinhq@kincanada.ca](mailto:kinhq@kincanada.ca)

[Vertex All in for CF Scholarship](#) helps persons with CF and their immediate family (siblings, caregivers, and children) in Canada and the United States pursue a two-year, four-year or graduate degree.

[LUMEN Society](#) provides financial assistance to high school graduates across Canada that have been impacted by an invisible illness directly or indirectly.

[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.

[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

For more information about higher education financial support opportunities, please visit [Cystic Fibrosis Canada's Blog](#) to view our post about scholarships, grants, awards and bursaries for the CF community.

## EMPLOYMENT SUPPORTS

[WORKink](#) is Canada's largest virtual employment resource centre for job seekers with disabilities.

[Episodic Disabilities Employment Network \(EDEN\)](#) is a website that allows Canadians with episodic disabilities to connect with each other to discuss employment issues, challenges and opportunities, as well as find information on employment services.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

There are mental health and emotional wellness resources for persons of all ages that are living with chronic-illnesses like CF and/or their caregivers. The following is a list of some of these resources:

### Adults

- [Antidepressant Skills Workbook \(ASW\)](#) available in English, French, Punjabi, Chinese, Vietnamese, and Farsi.
- [Anxiety Canada](#), formerly known as Anxiety BC, is now developing a national focus. They provide self-help resources, articles, videos, interactive tools, and apps for adults, youth, and children living with anxiety.
- [Calm](#) is a mindful meditation and sleep app (one free trial) with courses on mindfulness, self-esteem, happiness and more.
- [Canadian Association for Suicide Prevention](#) provides information on crisis centres in each province with phone numbers.
- [Canadian Mental Health Association \(CMHA\)](#) facilitates access to the programs, services and supports people require for mental health and emotional wellness.
- [Canadian Sleep Society](#) has resources for sleep management and improving sleep quality.
- [Centre for Addiction and Mental Health \(CAMH\)](#) provides online interactive videos and [courses](#) on mental health 101, depression 101, and more.
- [Centre for Disease Control](#) provides tips for better sleep.
- [Centre for Mindfulness Studies](#) helps with access to mental health services for those in need.
- [Depression, Anxiety and Cystic Fibrosis](#) – What the Guidelines Mean for You.
- [Depressionhurts.ca](#) provides information for identifying and managing depression. Information for family, friends and caregivers is also included.
- [Empowering Patients - Why Your Emotional Health Matters](#) is a source that has a playlist of 3 videos. These videos include book recommendations and may serve as an introduction to improving emotional health.
- [iMoodJournal](#) is a mood tracking mobile app with features such as automatic reminders, mood tracking, history charts and more.
- CF Canada's [virtual education program](#) for patients and caregivers on the [International Guidelines of Mental Health in CF](#).

- [Mental Health Commission of Canada \(MHCC\)](#) leads the development and dissemination of innovative programs and tools to support the mental health and wellness of Canadians.
- [Mindfulness-Based Cognitive Therapy \(MBCT\)](#) helps people who experience chronic unhappiness and repetitively feel depressed.
- [Omama](#) is a knowledge resource regarding pregnancy. This link specifically deals with postpartum depression and anxiety.
- [Psychology Foundation of Canada](#) resource includes programs to support and teach coping skills for parents. These include developmental stages from birth to adulthood.

## Youth and Children

- [BoosterBuddy](#) is a free app designed to help teens and young adults improve their mental health.
- [Fostering Resilience](#) prepares children and teens to cope through challenges. This resource is also useful for parents.
- [Kids Help Phone](#) is a Canadian charitable organization that provides free live chat online and telephone (1-800-668-6868) or text counselling services to children and youth across Canada 24/7.
- [Mindfulness for Teens](#) has videos and guided meditations.
- An [online interactive resource](#) for youth dealing with depression and anxiety.
- [Teen Mental Health](#) provides comprehensive information describing the various types of mental health issues teens can experience, including anxiety and depression.

## TRANSPLANT CENTRES AND RESOURCES

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.

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

### **Edmonton, Alberta:**

University of Alberta Hospitals

Telephone: 780-407-7559 (adult)

Telephone: 780-407-2581 (paediatric)

### **Vancouver, British Columbia:**

[Vancouver General Hospital](#) (adult/paediatric)

Telephone: 604-877-2240

Telephone: 1-800-663-6189

**Winnipeg, Manitoba:**  
[Health Sciences Centre](#) (adult/paediatric)  
Telephone: 204-787-1521

**Toronto, Ontario:**  
[Toronto General Hospital, University Health Network](#) (adult)  
Telephone: 416-340-4800 ext. 3807

[The Hospital for Sick Children](#) (paediatric)  
Telephone: 416-813-2233

**Montréal, Québec :**  
[Centre hospitalier de l'Université de Montréal](#) (adult/paediatric)  
Telephone: 514-890-8000

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.

Resources that may help reduce the financial costs associated with having to relocate for transplant and/or other transplant-related costs can be found under the Financial and Social Supports subheading in the national resources section of this guide and within provincial sections. Programs vary significantly in the type of support provided; whether money is delivered up front or reimbursed; and the application process and documentation required.

**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 setup 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 setup trust accounts. To setup 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.

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.



The following are transplant associations that may provide further guidance for those navigating transplant procedures:

[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

[Canadian Society of Transplantation \(CST\)](#) is an organization for professionals in the field of transplantation in Canada. CST plays a critical role in the development of national guidelines and safety issues involving the distribution of organs and tissues. They provide a list of provincial transplant programs and organ procurement organizations.

[Canadian Transplant Association \(CTA\)](#) offers programs to help organ donors and recipients after transplantation. CTA also works to raise awareness and celebrate the success of transplants

**Toll free:** 1-877-779-5991

# ALBERTA RESOURCES

## CF CLINICS

<b>Alberta Children’s Hospital</b> (paediatric)* Nurse Coordinator: Lori Fairservice Telephone: 403-955-7319	<b>Stollery Children’s Hospital</b> (paediatric) Nurse Coordinator: Amanda Jober Telephone: 780-407-4897
<b>Foothills Hospital</b> (adult) Nurse Coordinator: Linda Fatovich Telephone: 403-220-5951	<b>University of Alberta Hospitals</b> (adult) Nurse Coordinator: Crystal Howell Telephone: 780-407-6745

**Appendix G** is a list of all the CF clinics with contact information such as addresses and fax numbers included.

## OUTREACH CLINIC

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

## CLINIC RESOURCES

Health Professional	Alberta Children’s Hospital	Foothills Hospital	Stollery Children’s Hospital	University of Alberta Hospitals
Physiotherapist	✓	✓	✓	✓
Social Worker	✓	✓	✓	✓
Dietitian	✓	✓	✓	✓
Respirologist/ Pulmonologist	✓	✓	✓	✓
Gastroenterologist	✓	*	✓	*
Psychologist/Psychiatrist	✓	✓	*	*
Pharmacist	✓	✓	✗	*
Endocrinologist	*	✓	✗	*

\* on referral

## HOSPITAL FACILITIES

Service	Alberta Children's Hospital	Foothills Hospital	Stollery Children's Hospital	University of Alberta Hospitals
Rooming in when children are hospitalized	✓	N/A	✓	✓
Care-by-parent unit	✗	N/A	✓	✓
Hostel service	✓*	✗	✓*	✓
Educational program <i>e.g. Tutor</i>	✓**	✗	✓	✓
Recreational activities <i>e.g. Play program</i>	✓	✗	✓	✓
Special unit for teenagers	✓	✗	✗	✓***
Special unit for adults	✗	✓	✗	✓

\* 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.

Note: At the Stollery Children's Hospital, there is THE FAMILY ROOM which is dedicated to helping families find the information and resources they need while at the hospital, in addition to the social worker accessed through the CF clinic:

**Located on the 4<sup>th</sup> floor, Room 4H2.02**

**Telephone: 780-407-7255**

Note: At the Alberta Children's Hospital, there is a Family & Community Resource Centre (FCRC) located on the second floor that is committed to helping families find information, resources and support, in addition to the social work accessed through the CF clinic:

**Telephone: 403-955-FCRC**

**Toll free: 1-877-943-FCRC**

\*The FCRC has created an information prescription for pediatric CF that includes books.

**Please view Appendix F for a copy.**

## DRUG AND MEDICAL COVERAGE

The [Alberta Health Care Insurance Plan \(AHCIP\)](#) provides coverage for eligible Albertans for insured physician and hospital services. Registration requires confirmation of Albertan residency, identity, and legal right to be in Canada. Monthly premiums for the AHCIP are covered by the Alberta Government. [You can view the AHCIP application form online.](#)

For individuals with CF under 18 years of age, the provincial **CF Drug Program** covers antibiotics and enzymes. This applies only to antibiotics and enzymes – all other prescribed drugs are not covered without supplementary coverage such as with non-group Blue Cross or parental private insurance for medications.

Pulmozyme© is provided to individuals with CF under province-wide services. For other oral or intravenous medications, vitamins, and nutritional supplements, and for individuals over the age of 18, obtaining private or supplementary coverage is strongly encouraged.

One option for supplementary coverage is the [Non-Group Prescription Drug Coverage](#) offered through [Alberta Blue Cross](#). Under this plan, premiums (single or family rate) are paid on a quarterly basis. Premiums vary between \$45.00 and \$65.00 per month. There is a co-payment of 30 percent of the item cost, to a maximum of \$25, for each item prescribed. Co-payments are charged each time a prescription is filled. It is advisable to fill your prescriptions for the maximum 3 months times to avoid multiple co-payment charges. If a more expensive brand name drug is chosen instead of an equivalent generic drug, the additional cost must be paid for by the patient.

For general inquiries related to health care and health care insurance coverage, please contact Alberta Health directly:

**Telephone:** 780-427-1432 (Edmonton)  
**Toll free:** 310-0000, then 780-427-1432  
**E-mail:** [health.ahcipmail@gov.ab.ca](mailto:health.ahcipmail@gov.ab.ca)

**Alberta Community and Social Services** offers several programs that provide health benefits, including prescription medications, for the following client groups:

**[Alberta Works Emergency Prescription\(s\)/Drug:](#)** This benefit provides emergency medication coverage that commences on the first day of the month or when the application is accepted, and concludes on the last day of the month. [For recommendations on how to apply for this benefit please view Appendix A.](#)

**[Alberta Adult Health Benefit:](#)** Alberta Adult Health Benefit is a provincial program for low income Albertans that provides coverage for prescription medications, vitamins, diabetic supplies, emergency ambulance, dental services, and optical services. Unlike Alberta Works, Alberta Adult Health Benefit services are operated out of one central office located in Edmonton. [For recommendations on how to apply for this benefit please view Appendix B.](#)

**Alberta Child Health Benefit:** Alberta Children Health Benefit is a provincial program for low income Albertan families that provides health expenses coverage for prescription medications, vitamins, diabetic supplies, emergency ambulance, dental services, and optical services for children up to 18 years of age. Children that are 18 or 19 years old who live at home and attend high school are also eligible.

**Assured Income for the Severely Handicapped (AISH):** The eligibility for province-based disability benefits varies from province to province. While you may have received disability benefits in one province, this does not guarantee that you will automatically be eligible for and receive disability benefits in another province. In Alberta, AISH provides disabled adults with financial and/or health care benefits. Applicants must meet the financial and disability criteria set out by the AISH program. AISH assesses disability based on physical, mental, or a combination of both components. Disability is defined as prolonged, typically extending beyond 1 year. As such, it is important to discuss with your CF team the appropriateness of AISH for your situation.

**For recommendations on how to apply for this benefit please view Appendix C.**

**Alberta Works Income Support:** Alberta Works is a provincial program that provides emergent support for low income Albertans having difficulty meeting their basic needs like food, clothing and shelter. This resource includes income support, health benefits, and assistance and training to find employment. Eligibility for Alberta Works is determined by your assets and ability to return to work. You will need to visit an Alberta Works office, and be assessed by an Intake Worker. **For recommendations on how to apply for Alberta Works Income Support, please view Appendix D.**

For more information about any of the above Alberta Community and Social Services programs, please visit: **Ministry of Community and Social Services**

For more information on Alberta supplementary health benefits and prescription drug coverage, including links to the various programs listed above, please visit: **Alberta drug coverage and health benefits**

## FINANCIAL ASSISTANCE

**Alberta Works Income Support** is a provincial program that provides emergent support for low income Albertans having difficulty meeting their basic needs like food, clothing and shelter. This resource includes income support, health benefits, and assistance and training to find employment. Eligibility for Alberta Works is determined by your assets and ability to return to work. You will need to visit an Alberta Works office, and be assessed by an intake worker.

**Employment Insurance** is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, benefits for parents of critically ill children, and self-employed benefits.

**Assured Income for the Severely Handicapped (AISH)** provides disabled adults with financial and/or health care benefits. See information and link under the Alberta Drug and Medical Coverage section above. For further information on **how to apply, contact AISH** or speak with your CF team.

## EDUCATION AND EMPLOYMENT

**Bursaries, grants, and scholarships** can provide financial assistance with post-secondary education costs. Most of the applications for this type of financial support are now online, and high school and post-secondary counsellors can help guide students through the process. It is important to note that there are a multitude of financial awards that go unclaimed every year, so by putting in the time and energy to apply for even smaller awards, students can often fund at least part of their higher education. For additional financial support opportunities, please visit the Educational Awards section under Canada-wide resources, within this guide.

**Note to students:** It is particularly important for students to connect with their disability advisor at their educational institution, or their potential institution. The disability advisor will assist students with CF navigate and apply for local, provincial and/or federal grants and assistance. Disability grants are available through the provincial and federal government.

[Alberta Student Aid](#) supports students with permanent disabilities.

[Alberta Learning Information Service \(ALIS\)](#) provides assistance to individuals seeking employment, educational programs and schools that are specific to Alberta.

### [Alberta Supports Contact Centre](#)

Telephone: 780-644-9992

Toll free: 1-877-644-9992

[Alberta Works](#) is an additional resource that provides: in-person support, online resources, telephone services, disability related employment supports, financial support for training, and paid training and work experience.

[Entrepreneurs with Disabilities Program \(EDP\)](#) provides western Canadians with disabilities 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 [Community Future offices](#) in rural communities and [regional EDP offices](#) in urban areas of western Canada.

[Employment Insurance](#) is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for In-depth information on employment insurance, eligibility, and specific benefits.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

In addition to the following resources, visit the [Canada-wide mental health and emotional wellness section](#).

### Adults

- [Access Mental Health](#) is a telephone based, non-urgent service that provides information, consultation, and referral to mental health and/or addiction programs within the Calgary area: call 403-943-1500.
- [Alberta Health Services – Addiction and Mental Health](#) is an online website for patients and families regarding mental health and addiction services within Alberta.
- [Canadian Mental Health Association](#) provides mental health services for Albertans across the province.
- [Distress Centres](#) a program that provides support to Calgary and southern Alberta. Services encompass urgent and/or ongoing support through a crisis line, face-to-face counselling, a scheduled online chat, and email. The 24 hours crisis line offers service in over 200 languages: Crisis Line – 403-266-HELP (4357). All services are free.
- **Mental Health Help** Line is a 24 hours telephone service for programs across Alberta: call 1-877-303-2642.
- [My Health](#) is a website for Alberta wide resources.

### Youth and Children

- [ConnecTeen](#) provides a service for Teens and youth to receive adult or peer support through a 24 hours crisis line, online chat, email, or text: 403-264-TEEN (8336).
- [Help4me.ca](#) provides youth and mental health support through the My Health Alberta website includes resources for friends, family, self-care resources, and healthcare finder.

## MEDICAL EQUIPMENT, SUPPLIES AND OXYGEN

[Alberta Aids to Daily Living \(AADL\)](#) encourages and facilitates the independence of Albertans with long-term disability, chronic or terminal illness. The program connects eligible patients to authorized vendors, who then provide oxygen and respiratory equipment. There is a 25% copay for patients to a maximum cost of \$500 per individual or family per year. However, Albertans with low-income or who are receiving income assistance are exempt from the copay. Cost share exemption forms are required to be filled out by low-income families.

**Telephone:** 780-427-0731 (Edmonton and area)  
**Toll free:** 310-0000, then 780-427-0731

## NUTRITIONAL SUPPLEMENTS

For Adults, over the age of 18, with CF requiring enteral feeding, financial assistance may be provided through the [Southern Alberta Adult Home Enteral and Parenteral Nutrition Program](#) 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 or visit [Alberta Health Services](#).

## HOME CARE

[Homecare through Alberta Health Services \(AHS\)](#) provides medical support through a multi-disciplinary team to help people live independently at home. Eligible services are determined by Home Care Coordinators.

## SOCIAL SUPPORTS

Contact your local [Cystic Fibrosis Canada Chapter](#) or [CF clinic](#) for details of the existing social support network in the area. There are 11 chapters in the Western Region. [Please see the back of the CF Resource 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 through [your local FSCD office](#).

[Starlight Children's Foundation](#) provides services for seriously ill children and their families. The Starlight Foundation runs In-Hospital Programs, Out-of-Hospital Programs and includes online resources for families in Alberta.

### *Starlight Children's Foundation – Alberta*

**Name:** Heather Burnett  
**Toll free:** 1-800-880-1004 ext. 4240  
**E-mail:** [heather.burnett@starlightcanada.org](mailto:heather.burnett@starlightcanada.org)

## ADVOCACY

[Alberta Civil Liberties Research Centre](#) provides information, teaching and materials, video resources, 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.

**Telephone:** 403-220-2505  
**Fax:** 403-284-0945  
**E-mail:** [aclrc@ucalgary.ca](mailto:aclrc@ucalgary.ca)



**Alberta Disabilities Forum (ADF)** is a coalition of 73 not-for-profit provincial disability organizations whose members speak with a unified voice on cross-disability issues of concern for Albertans with disabilities.

**Telephone:** 780-488-9088  
**E-mail:** [adf@vadsociety.ca](mailto:adf@vadsociety.ca)

**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.

**Telephone for confidential lines:** 780-427-7661 (Northern Alberta)  
403-297-6571 (Southern Alberta)  
**Telephone for education & engagement:** 403-297-8407  
**E-mail:** [humanrights@gov.ab.ca](mailto:humanrights@gov.ab.ca)

**Cystic Fibrosis Canada** has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or call Cystic Fibrosis Canada at 1-800-378-2233.

**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.

**Telephone:** 780-422-1095  
**Toll free:** 310-0000 then, 780-422-1095  
**E-mail:** [pcspd@gov.ab.ca](mailto:pcspd@gov.ab.ca)

**Voice of Albertans with Disabilities (VAD)** is an 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. VAD assists persons with disabilities seeking expertise on services, supports or federal and provincial application forms through their **individual supports program**, and award **Education for Life Bursaries** every year. One-on-one appointments are available.

**Telephone:** 780-488-9088  
**Toll free:** 1-800-387 2514  
**E-mail:** [vad@vadsociety.ca](mailto:vad@vadsociety.ca)

## NEWBORN SCREENING

Alberta screens newborns for cystic fibrosis. Please contact a [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

Genetic counselling and testing is available at no charge to residents of Alberta on referral through a CF physician. Alberta also supports a neonatal testing program that includes CF in its testing panels. Testing is available in Alberta at the following laboratories:

**Medical Genetics Clinic**  
**University of Alberta**  
853 Medical Sciences Building  
Edmonton, Alberta T6G 2B7  
**Telephone:** 780-407-7333

**Medical Genetics**  
**Alberta Children's Hospital**  
2888 Shaganappi Trail NW  
Calgary, Alberta T3B 6A8  
**Telephone:** 413-955-7373

## TRANSPLANT CENTRES

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.

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

**Edmonton, Alberta:**  
**University of Alberta Hospitals**  
**Telephone:** 780-407-7559 (adult)  
**Telephone:** 780-407-2581 (paediatric)

**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.

**Telephone:** 780-407-6593

# BRITISH COLUMBIA RESOURCES

## CF CLINICS

(The **Victoria Adult Clinic site** includes contact information for the *Victoria Pediatric CF Clinic*)

<p><b>BC Children's Hospital</b> (paediatric)  <b>Nurse Coordinator:</b> Anna Gravelle  <b>Telephone:</b> 604-875-2345 ext. 7005</p>	<p><b>Victoria General Hospital</b> (paediatric)  <b>Nurse Coordinator:</b> Alison Manning  <b>Telephone:</b> 250-727-4451 or                  250-727-4450</p>
<p><b>St. Paul's Hospital</b> (adult)  <b>Nurse Coordinator:</b> Jane Kerr  <b>Telephone:</b> 604-682-2344 ext. 63892</p>	<p><b>Royal Jubilee Hospital</b> (adult)  <b>Nurse Coordinator:</b> Grant Hoffert  <b>Telephone:</b> 250-370-8111 ext. 13395</p>

**Appendix G** is a list of all the CF clinics with contact information such as addresses and fax numbers included.

## OUTREACH CLINICS

**BC Children's Hospital** (Paediatric) - Outreach clinics are held three times yearly in Kelowna and Prince George.

**Adult CF Clinic at St. Paul's Hospital** - Outreach clinics are held approximately four times per year in Kelowna and periodically in Prince George.

## CLINIC RESOURCES

Health Professional	BC Children's Hospital	St. Paul's Hospital	Victoria General Hospital	Royal Jubilee Hospitals
Physiotherapist	✓	✓	✓	✓
Social Worker	✓	✓	✓	✓
Dietitian	✓	✓	✓	✓
Respirologist/Pulmonologist	✓	✓	✓	✓
Gastroenterologist	*	*	*	*
Psychologist/Psychiatrist	✓	✓	✓	*
Pharmacist	✓	✓	✓	*
Endocrinologist	*	*	*	*
Spiritual Care	✓	✓	✗	✗
Aboriginal Health (Liaison Program)	✓	✓	✗	✗

\* on referral

## HOSPITAL FACILITIES

Service	BC Children's Hospital	St. Paul's Hospital	Victoria General Hospital	Royal Jubilee Hospitals
Rooming in when children are hospitalized	✓	✓	✓	N/A
Care-by-parent unit	✗	N/A	✗	N/A
Hostel service <i>e.g. Easter Seals House, Janece Place</i>	✓	✓	✓	✗
Educational program <i>e.g. Tutor</i>	✓	✗	✓	✗
Recreational activities <i>e.g. Play program</i>	✓	✗	✓	✗
Special unit for teenagers	✗	✗	✗	✗
Special unit for adults	✗	✓	✗	✓

At all four BC CF clinics hospital admitted patients have their own room and bathroom. At BC Children's and St. Paul's any patient who is colonized with B. cepacia complex is admitted to a ward with no other CF patients on it. At Royal Jubilee patients colonized with B. cepacia complex are on the same floor, but on different wings of the ward (there are east/west wings) and do not have the same RN or break relief RN. At Victoria General there is one inpatient pediatric ward, but two sides to the ward with two separate nursing teams on each side.

At all four BC CF Clinics patients are asked to wear a mask to and from clinic and in common areas in the hospital for infection control purposes.

### Cystic Fibrosis Patient Advisory Committee (CFPac)

All four CF clinics aim to have a patient centered approach to care.

Currently the St. Paul's Hospital Adult CF Clinic has an active adult CFPac. The CFPac is made up of people living with CF who attend the St. Paul's clinic, with room for representation from parents, spouses or other family members. The CFPac aims to enhance the CF patient care experience by incorporating the perspectives of people living with CF and their families into the planning and delivery of CF care. The CFPac meets via video or teleconference due to infection control.

Individuals interested in contacting the CFPac at St. Paul's Hospital can do so at [cfpacbc@gmail.com](mailto:cfpacbc@gmail.com).

If you attend one of the other three BC clinics, check with your clinic to see if there is currently an active CFPac, as this can change.

## DRUG AND MEDICAL COVERAGE

All residents of BC need to be registered with both the Medical Services Plan (MSP) and Fair Pharmacare to ensure they are properly covered for their medical needs. If a person is on Persons with Disabilities (PWD) benefits, they do not pay for any Fair Pharmacare covered medications or for MSP monthly premiums.

**Medical Services Plan (MSP)** is coverage for services such as doctor's visits, hospitalizations and lab tests for BC residents. BC residents must apply for MSP to get medical coverage and pay a monthly premium, which is calculated depending on income. (The BC government has indicated they are phasing out MSP premiums by 2020.) For individuals from elsewhere in Canada but new to BC, the wait period to qualify for MSP consists of the balance of the month in which residence is established, plus two months. It is recommended individuals arriving in the province apply for MSP as soon as they arrive in the province.

The **BC Pharmacare program** subsidizes eligible prescription drugs for all qualified BC residents. Patients should always apply for what is called Fair Pharmacare. Fair Pharmacare is a program that sets a yearly deductible based on a patient's annual income, after which all eligible prescriptions are covered by Pharmacare. This includes a very small number of specific supplies and equipment. It is important to note that Insulin pumps are now approved for coverage in BC for both children and adults who fit the criteria.

**Fair Pharmacare** is based on net (family) income from two years back. (For example, 2018 is based on a patient's 2016 tax return information). It 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, and at which point Fair Pharmacare pays 100%).

**To be eligible for Pharmacare and Fair 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 with other status such as student visas and work 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).

### Specialty Plans under Pharmacare Relevant to People Living with CF

**Plan C** – People on income assistance or on provincial Persons with Disability benefits (PWD) are provided 100% financial coverage of eligible prescription drugs.

#### **Plan D** – Cystic Fibrosis Formulary

Individuals with cystic fibrosis who are registered with a provincial clinic receive coverage, after their Fair Pharmacare deductible has been reached, for products listed in the CF Formulary. The only exception to this is enzymes, which do not have a deductible and are covered 100% for people with CF in BC.

To obtain CF supplements through Plan D, individuals must be registered at a BC CF clinic, their clinic must register them for Plan D with Pharmacare, they must attend a BC CF clinic at specified intervals, and have prescriptions written by a CF clinic physician.

**Special Authority:** Some medications that are not covered under Pharmacare and some supplements not listed in the Plan D CF 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. Special authorities can be discussed with the CF physician or pharmacist.

You may contact **Health Insurance BC** by phone for questions and/or issues with MSP or Fair Pharmacare:

**Toll free:** 1-800-663-7100  
**Vancouver:** 604-683-7151

**Extended Health Benefits:** Some people have extended health benefits through their workplace which may provide them with extra coverage for medications or other therapies. Each benefit plan is different, so individuals should check with their employer or Human Resources (HR) department to find out what is covered.

## FINANCIAL ASSISTANCE

The **BC Travel and Medication Grant** assists individuals with CF and their families in BC with the costs of CF-related prescribed medications, as well as travel and accommodation for visits to CF clinics and CF-related hospitalizations. To qualify, individuals must attend one of the four accredited CF clinics in BC at least once a year, register with Fair PharmaCare, and submit a Grant Registration Form. A Grant Reimbursement Form is required with each claim. Reimbursement is in accordance with and subject to the limitations of the Grant. For more information, please contact your CF clinic team.

Copies of the BC Government Grant Policy & Forms are available through the [St. Paul's Hospital CF Clinic website](#).

**Persons with Disabilities (PWD)** is a provincial disability benefit program for adults. Individuals must live in BC to qualify. A person may be eligible for disability benefits provided through the Ministry of Social Development and Poverty Reduction (MSDPR) in BC if daily activities are impacted significantly due to illness or disability. There must also be financial need.

Legal Services Society has put out an easy to read series of guides online for people on Income Assistance or PWD called Your Welfare Rights. Any special rules that apply specifically to PWD are highlighted in the following [publication](#).

To make an online application for [Income Assistance \(IA\)](#) in order to apply for PWD benefits individuals should talk to their CF social worker first to see if they might qualify.

**Government support** may be available through the Ministry of Social Development and Poverty Reduction or the Ministry of Child and Family Development for the pediatric population depending on the family situation and child's specific medical situation. For more information, families should contact the pediatric social worker at their child's CF clinic.

**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.

**Telephone:** 604-742-0272  
**Toll free:** 1-800-880-1004 ext. 4240  
**Fax:** 604-742-0274  
**E-mail:** [heather@starlightcanada.org](mailto:heather@starlightcanada.org) or  
[Debbie@starlightcanada.org](mailto:Debbie@starlightcanada.org) (Great Escapes)

**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.

**Telephone:** 604-268-3893  
**Toll free:** 1-800-381-2040  
**E-mail:** [heart.fund@variety.bc.ca](mailto:heart.fund@variety.bc.ca)

A number of **other paediatric focused charities** exist to support families from across BC who have children with extraordinary medical needs and who are also financially in need. This can include trips for medical care and covering medical related supplies such as, equipment and prescriptions, Families should contact their paediatric CF Clinic Social Worker to have a referral made to one of these organizations, or to find out about other active charities, as this list can change.

<b>Friends of Children</b>	Northern BC and East Kootenay
<b>COPS for Kids</b>	Southern Interior Region of British Columbia
<b>Bare Essentials</b>	Vancouver Island and the Yukon

### **Financial Assistance for Medical Travel:**

**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. If you require a TAP form please ask your CF team as one can be either mailed to you or provided to you in person. It is especially beneficial for people who need to travel by ferry.

**Health Connections Bus** offers subsidized transportation options to help defray costs for rural residents who must travel to receive medical care outside their home communities. This includes the Wheels for Wellness program on Vancouver Island.

## Financial Assistance for Medical Accommodations:

**Medical Hotel Rates** may be available. CF Clinic social workers generally have lists of hotels near the hospitals that offer medical rates to patients. Often these hotels only require you to explain where you are a patient, and that you are in town for medical reasons to get the rate. Others may require a call from your CF clinic.

**Easter Seals House** is available to both adults and children as a low cost option for accommodation during medical trips to Vancouver. This accommodation is closer to BC Children's Hospital than to St. Paul's Hospital, but adults with CF still may use it due to the low cost. They then travel by car or transit to St. Paul's during their stay.

**Jenece Place** is a home where children and their families can stay while receiving medical care in Victoria. It is owned and operated by Children's Health Foundation and is located on the Victoria General Hospital grounds. There are 10 bedrooms and a kitchen, as well as dining, living and play rooms. There is also a backyard where kids can play.

**BC Family Residence 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. Any family living 70km away from BC Children's Hospital 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, please contact:

**Telephone:** 1-800-465-4911

## Financial Assistance for Housing:

**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. There is an extremely long wait list for BC Housing, sometimes a number of years. Therefore individuals should apply as soon as they are aware of their need for housing. BC Housing asks applicants to contact them every six months to stay active on the wait list.

**Toll free:** 1-800-257-7756  
**Telephone:** 604-433-2218 (Vancouver)

## Financial Assistance for Food:

**Quest Food Exchange** runs five not-for-profit food markets in the lower mainland of BC. Their aim is to provide healthy and affordable food in a respectful environment through their low-cost grocery markets to people in financial need. Individuals must be referred by their CF clinic or another community partner. Individuals or families living in the lower mainland can ask their CF clinic social worker for a referral if they feel they might qualify.



**Food Banks** exists throughout BC and the CF clinic social workers can direct individuals in need to the appropriate resource.

For more information on food banks available to families within Vancouver, please use the [food asset map](#).

## EDUCATION AND EMPLOYMENT

**Vocational and educational counselling** is available to young people through counsellors at their high schools, or through post-secondary institutions.

**Bursaries, grants, and scholarships** can provide financial assistance with post-secondary education costs. This includes funding for the trades. Most of the applications for this type of financial support are now online, and high school and post-secondary counsellors can help guide students through the process. It is important to note that there are a multitude of financial awards that go unclaimed every year, so by putting in the time and energy to apply for even smaller awards, students can often fund at least part of their higher education. For financial support opportunities, please visit the Educational Awards section under Canada-wide resources, within this guide.

[WorkBC](#) offers both online and in-person resources to help individuals looking to enter or re-enter the workforce. They assist with career planning and job searches, with a focus on providing tools clients can utilize in a self-directed manner. At some WorkBC sites specialized services and supports are available to job seekers with specific needs, such as people living with disabilities and chronic conditions. When looking for specialized supports, individuals should ask to be directed to a site where Personal Services and Supports are in place, as site programs can differ.

[The Ministry of Social Development and Poverty Reduction \(MSDPR\)](#) offers some employment programs to people on Persons with Disabilities (PWD). This is because people on PWD are allowed to earn a certain amount of money per year. For example, at this writing the Self-Employment Program (SEP) is in place, which allows people on PWD to run their own business. These types of programs tend to change periodically so check for up-to-date information on employment support programs through MSDPR.

[Entrepreneurs with Disabilities Program \(EDP\)](#) provides western Canadians with disabilities 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 [Community Future offices](#) in rural communities and [regional EDP offices](#) in urban areas of western Canada.

[Employment Insurance](#) is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for In-depth information on employment insurance, eligibility, and specific benefits.

# MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

In addition to the following resources, [visit the Canada-wide mental health and emotional wellness section](#).

All four CF clinics in BC have developed and are in the process of implementing screening guidelines for anxiety and depression in CF patients. At the pediatric clinics these screening efforts also include caregivers. This follows the international mental health guidelines for CF.

Individuals and families can ask their CF clinic team about the status of the screening program at their clinic, as well as about what resources and supports are available to support emotional wellness. Three of the four BC clinics also have psychiatrists or psychologists on their teams. Please see the Hospital Facilities section for information on this.

In development is a BC specific counselling program/therapist database, to better meet the counselling needs of people living with CF in their home communities. Families and individuals can also explore the counselling related links below:

- [BC Regional Health Authorities](#) (Public mental health programs vary within each community)
- [Counselling BC](#) (**Directory**) (Fee for service)
- [Canadian Psychological Association \(CPA\) Directory](#) (Fee for service)

The **Crisis Line Association of BC (CLABC)** provides emotional support, crisis and suicide assessment/intervention and resource information to people across BC. They run two province-wide lines:

**1-800-suicide:** 1-800-784-2433 for individuals considering suicide or worried about someone who may be.

**310 Mental Health Support:** 310-6789 (no need to dial the area code) for emotional support, information, and resources specific to mental health.

They also provide a map and list of [local crisis lines](#) across the province.

## Adults

- [Anxiety Canada](#) provides online self-help and evidence-based resources on anxiety.
- [Bounce Back®](#) teaches effective skills to help individuals (aged 15+) overcome symptoms of mild to moderate depression or anxiety, and improve their mental health. Participants can learn skills to help combat unhelpful thinking, manage worry and anxiety, and become more active and assertive.
- [North Shore Stress and Anxiety Clinichas](#) experienced clinicians for adults, in addition to 13 psychologists who see children and adolescents.
- [Self-Management BC](#) provides knowledge, skills, and confidence to successfully manage chronic health conditions.

## Youth and Children

- [Anxiety Canada MindShift App](#) is designed to help teens and young adults cope with anxiety.
- [Anxiety Canada Youth](#) provides online self-help and evidence-based resources on anxiety for youth.
- [BC Children’s Hospital Library](#) has books that pertain to anxiety.
- [Children and Youth with Mental Health](#): This website links to many resources that help children with mental health issues or who are in a mental health crises, including resources for suicide prevention.
- [Kelty Mental Health Resource](#) center offers health and wellness resources, services and supports. Parents may find this resource useful.

## MEDICAL EQUIPMENT, SUPPLIES AND OXYGEN

Generally, individuals are responsible for covering the cost of much their home medical equipment and supplies, such as Pep masks and nebulizing systems. However, the public system may cover some supplies; for example a certain number of tests strips per year (after the deductible is reached) are covered for diabetes, and insulin pumps are covered for qualified patients under Pharmacare. The CF Travel and Medication Grant may help with nebulizing systems if no other resources are available, and extended health benefit plans may cover some or all of the costs of certain equipment and supplies. Therefore it is important for individuals to explore their various plans and benefit programs, or ask their CF clinic social worker for assistance.

Oxygen is only covered by the [BC Home Oxygen](#) program if a patient qualifies medically. If an individual does not qualify medically but still wishes to have oxygen at home, they will need to pay for it themselves or apply to their extended health plan if they have one.

## NUTRITIONAL SUPPLEMENTS

*For information on nutritional supplements, please contact your CF care team.*

## HOME CARE

In general home care through the public system in BC is limited to specific services: mainly assistance with bathing, dressing, and feeding. An individual must be assessed and qualify medically to receive public homecare services, otherwise they need to pay privately. Services such as community palliative care and hospice are available under the public system if an individual qualifies medically.

There are Home IV programs in many, but not all, communities in BC.

## SOCIAL SUPPORTS

Contact your local [Cystic Fibrosis Canada Chapter](#) or [CF clinic](#) for details of the existing social support network in the area. There are 11 chapters in the Western Region. [Please see the back of the CF Resource Guide for a listing of all chapters across Canada.](#)

## ADVOCACY

[Cystic Fibrosis Canada](#) has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or call Cystic Fibrosis Canada at 1-800-378-2233.

[Disability Alliance BC \(DABC\)](#) supports people with all disabilities to live with dignity, independence, and as equal and full participants in the community. They do this through direct services, community partnerships, advocacy, research and publications. Of particular interest to people living with CF are their programs providing resources on PWD and CPPD, as well as DTC and RDSP information and education.

**Telephone:** 604-872-1278 (Vancouver)  
**Toll free:** 1-800-663-1278

[BC Human Rights Tribunal](#) is an independent body created by the [B.C. Human Rights Code](#) that works to foster equality and reduce discrimination by accepting, screening, mediating, and adjudicating human rights complaints.

**Telephone:** 604-775-2000  
**Toll free:** 1-888-440-8844  
**E-mail:** [BCHumanRightsTribunal@gov.bc.ca](mailto:BCHumanRightsTribunal@gov.bc.ca)

## NEWBORN SCREENING

British Columbia screens newborns for cystic fibrosis. Please contact a [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

Genetic testing is organized through the clinic if it is needed to confirm a diagnosis of CF or to ascertain specific CF mutations. If genetic testing is required for these purposes there is no cost to the patient.

Carrier testing for the partners or siblings of patients is generally done on referral from a family physician and there is no cost to the patient.

## TRANSPLANT CENTRE

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.

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

**Vancouver, British Columbia:**

[Vancouver General Hospital](#) (adult/paediatric)

**Telephone:** 604-877-2240

**Toll free:** 1-800-663-6189

# MANITOBA RESOURCES

## CF CLINICS

<p><b>Children’s Hospital of Winnipeg</b> (paediatric)</p> <p>Nurse Coordinator: Jane Mayo Jocelyne Arpin</p> <p>Telephone: 204-787-2079 204-787-2485</p>	<p><b>Health Sciences Centre</b> (adult)</p> <p>Nurse Coordinator: Jody Hainstock</p> <p>Telephone: 204-787-1521</p>
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[Appendix G](#) is a list of all the CF clinics with contact information such as addresses and fax numbers included.

## CLINIC RESOURCES

Health Professional	Children’s Hospital of Winnipeg	Health Sciences Centre
Physiotherapist	✓	✓
Social Worker	✓	✓
Dietitian	✓	✓
Respirologist/Pulmonologist	✓	✓
Gastroenterologist	*	✓
Psychologist/Psychiatrist	*	*
Child Life Therapist	✓	—
Pharmacist	✓	*
Endocrinologist	*	*
Spiritual and Mental Health Nurse	✓	—
Teacher	✓	—
Homecare Nurse	✓	—

\* on referral

## HOSPITAL FACILITIES

Service	Children's Hospital of Winnipeg	Health Sciences Centre
Rooming in when children are hospitalized	✓	✓
Care-by-parent unit	✗	N/A
Hostel service	✓	✓
Educational program <i>e.g. Tutor</i>	✓	✗
Recreational activities <i>e.g. Play program</i>	✓	✗
Special unit for teenagers	✗	✗
Special unit for adults	✗	✓

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

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

## DRUG AND MEDICAL COVERAGE

[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, Seniors and Active Living coverage, and not have prescriptions covered through other provincial or federal programs. 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, Seniors and Active Living Provincial Drug Program](#)

Telephone: 204-786-7141

Toll free: 1-800-297-8099

E-mail: [pharmacare@gov.mb.ca](mailto:pharmacare@gov.mb.ca)

## FINANCIAL ASSISTANCE

[The Employment and Income Assistance Program \(EIA\)](#) provides financial help to Manitobans who have no other way to support themselves or their families.

[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.

**Telephone:** 204-787-4271

The [Government of Manitoba's](#) information for Manitobans with Disabilities website page lists services and resources available for people with disabilities.

[A Port in the Storm](#) aims to reduce the financial burden of serious illness on those who must travel to and remain in Winnipeg to receive medical care. It is a safe haven for rural and northern adults living in Manitoba and Northwestern Ontario.

**E-mail:** [admin@aportinthestorm.ca](mailto:admin@aportinthestorm.ca)  
**Telephone:** 204-231-0720  
**Fax:** 204-594-6435  
**Address:** A Port in the Storm  
 311 Alexander Avenue  
 Winnipeg, Manitoba  
 R3A 0M9

[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.

**Telephone:** 204-772-1899  
**Toll free:** 800-552-6820

## EDUCATION AND 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.

[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.

**Telephone:** 204-975-3010  
**Toll free:** 1-866-282-8041  
**E-mail:** [info@smd.mb.ca](mailto:info@smd.mb.ca)



**Entrepreneurs with Disabilities Program (EDP)** provides western Canadians with disabilities 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 **Community Future offices** in rural communities and **regional EDP offices** in urban areas of western Canada.

**Entrepreneurs with Disabilities Program**  
**Community Futures Manitoba**

**Toll free:** 1-888-303-2232  
**E-mail:** [edpinfo@mts.net](mailto:edpinfo@mts.net)

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

**Employment Assistance for People with Disabilities** is an operating manual that provides a list of employment services aimed at assisting adults with disabilities to prepare and find employment.

**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.

**Telephone:** 204- 832-REES (7337)  
**E-mail:** [info@re-es.org](mailto:info@re-es.org)

**Employment Insurance** is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for In-depth information on employment insurance, eligibility, and specific benefits.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

In addition to the following resource, **visit the Canada-wide mental health and emotional wellness section on.**

- **Bounce Back®** teaches effective skills to help individuals (aged 15+) overcome symptoms of mild to moderate depression or anxiety, and improve their mental health. Participants can learn skills to help combat unhelpful thinking, manage worry and anxiety, and become more active and assertive.

## MEDICAL EQUIPMENT, SUPPLIES 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 clinic nurse coordinator.

## NUTRITIONAL SUPPLEMENTS

**Manitoba Home Nutrition Program** is a community program for both short and indefinite duration that supports clients who require nutrition or hydration support, either to supplement oral intake or to completely replace oral intake by either tube feeding, Total Parenteral Nutrition (TPN) or Intravenous Hydration. Eligibility includes; being Manitoba residence with a valid PHIN, have medical documentation of inability to meet 100% of nutritional requirements by mouth and is medical stable. Referral has to be made by a physician or interdisciplinary hospital team member for both adult and paediatric patients. MHNP funds formula only for clients who are not eligible under other programs. MHNP does not provide funding for supplies for any clients.

Dietary supplements are not covered under Pharmacare, however, will be covered for those receiving Employment and Income Assistance (EIA) or possibly private health coverage.

## HOME CARE

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. An assessment through their regional health authority office is required to determine eligibility. People with the Manitoba Health coverage are provided services without charge by **Home Care Services in Manitoba**. For more information about the services available, requirements, and application process, please view the **Home Care Services in Manitoba Guide**.

## SOCIAL SUPPORTS

Contact your local **Cystic Fibrosis Canada Chapter** or **CF clinic** for details of the existing social support network in the area. There are 11 chapters in the Western Region. **Please see the back of the CF Resource Guide for a listing of all chapters across Canada.**

## ADVOCACY

**Cystic Fibrosis Canada** has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact **advocacy@cysticfibrosis.ca** or call Cystic Fibrosis Canada at 1-800-378-2233.

[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.

**Telephone:** 204-945-3007 (Winnipeg) or 204-726-6261 (Brandon)  
**Toll free:** 1-888-884-8681  
**E-mail:** [hrc@gov.mb.ca](mailto:hrc@gov.mb.ca)

[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.

**Telephone:** 204-943-6099  
**E-mail:** [contact@mlpd.mb.ca](mailto:contact@mlpd.mb.ca)

## NEWBORN SCREENING

Manitoba screens newborns for cystic fibrosis. Please contact a [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

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:

**Address:** **Health Sciences Centre**  
 Molecular Diagnostic Laboratory  
 820 Sherbrook Street  
 Winnipeg, Manitoba R3A 1R9  
**Telephone:** 204-787-2494  
**Fax:** 204-787-1419

## TRANSPLANT CENTRE

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.

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

**Winnipeg, Manitoba:**  
[Health Sciences Centre](#) (adult/paediatric)  
**Telephone:** 204-787-1521

# NEW BRUNSWICK RESOURCES

## CF CLINIC

**Horizon Health Network** (paediatric and adult)  
**Saint John Regional Hospital**  
Nurse Coordinator: Beth MacCready  
Telephone: 506-648-6057

**Appendix G** is a list of all the CF clinics with contact information such as addresses and fax numbers included.

## OUTREACH CLINICS:

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

*Some adult patients travel to Quebec and/or Halifax CF clinics.*

## CLINIC RESOURCES

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

\* on referral

## HOSPITAL FACILITIES

Service	Saint John Regional Hospital
Rooming in when children are hospitalized	✓
Care-by-parent unit	✗
Hostel service	✗
Educational program <i>e.g. Tutor</i>	✓
Recreational activities <i>e.g. Play program</i>	✓
Special unit for teenagers	✓
Special unit for adults	✗

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

## DRUG AND MEDICAL COVERAGE

**New Brunswick Prescription Drug Program (NBPDP) – Cystic Fibrosis Plan** 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 the **Cystic Fibrosis Plan** 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.

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, **Organ Transplant Plan**. The same qualifications as noted for the Cystic Fibrosis Plan apply to this program.

**New Brunswick Prescription Drug Program** (Administration Office)

**Telephone:** 506-867-4515

**Toll free:** 1-800-332-3692

**E-mail:** [info@nbdrugs-medicamentsnb.ca](mailto:info@nbdrugs-medicamentsnb.ca)

## FINANCIAL ASSISTANCE

In addition to the following resource, please visit the [Canada-wide Financial and Social Supports section](#) of this guide.

[Department of Social Development](#) offers various programs to assist with financial need, housing and other concerns related to disability or hospitalization.

## EDUCATION AND EMPLOYMENT

**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](#)

Telephone: 506-453-2597

E-mail: [dpetlinfo@gnb.ca](mailto:dpetlinfo@gnb.ca)

[Department of Social Development](#)

*Several locations are available throughout the province.*

**Employment Insurance** is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for In-depth information on employment insurance, eligibility, and specific benefits.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

In addition to the following resource, [visit the Canada-wide mental health and emotional wellness section](#)

- [Community Mental Health Centres \(CMHC\)](#) is a community based program for people of all ages that have mental health concerns.

## MEDICAL EQUIPMENT, SUPPLIES 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](#). For more information, please contact your CF clinic.

Oxygen, some medical equipment and supplies are available through the Department of Social Development's [Health Services Respiratory Program](#) to individuals who receive assistance through the Department of Social Development, and their dependents. The program assists with coverage of respiratory equipment and supplies not covered by NB Medicare or private health insurance. It covers: concentrators; oxygen cylinder refills; oxygen saturation monitors; chest vibrators; cough assist machines; and other related supplies. Individuals 65 years of age or over are not eligible for this program.

### Department of Social Development

Telephone: 506-453-2001

E-mail: [sd-ds@gnb.ca](mailto:sd-ds@gnb.ca)

## NUTRITIONAL SUPPLEMENTS

*For information on nutritional supplements, please contact your CF care team.*

## HOME CARE

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. For more information, please contact your CF clinic.

## SOCIAL SUPPORTS

Contact your local [Cystic Fibrosis Canada Chapter](#) or [CF clinic](#) for details of the existing social support network in the area. There are 9 chapters in the Atlantic Region. [Please see the back of this Guide for a listing of all chapters across Canada.](#)

## ADVOCACY

[Cystic Fibrosis Canada](#) has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or call Cystic Fibrosis Canada at 1-800-378-2233.

[Client Advocate Services](#) exists to inform patients of their rights when dealing with New Brunswick Medicare.

[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.

Telephone: 506-453-2301

Toll free: 1-888-471-2233

Fax: 506-453-2653

[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.

**Telephone:** 506-444-3000  
**Toll free:** 1-800-442-4412  
**Fax:** 506-444-3001  
**E-mail:** [pcsdp@gnb.ca](mailto:pcsdp@gnb.ca)

## NEWBORN SCREENING

New Brunswick screens newborns for cystic fibrosis. Please contact a [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

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.

## TRANSPLANT CENTRES

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.

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



# NEWFOUNDLAND AND LABRADOR RESOURCES

## CF CLINIC

**The Janeway Site** (paediatric)  
**Health Sciences Centre** (adult)  
Nurse Coordinator: Karen Doyle  
Telephone: 709-777-4389

[Appendix G](#) is a list of all the CF clinics with contact information such as addresses and fax numbers included.

## OUTREACH CLINIC:

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

## CLINIC RESOURCES

Health Professional	The Janeway Site	Health Sciences Centre
Physiotherapist	✓	✓
Social Worker	✓	✓
Dietitian	✓	✓
Respirologist/Pulmonologist	*	✓
Gastroenterologist	*	*
Psychologist/Psychiatrist	*	*
Pharmacist	✓	✓
Endocrinologist	*	*

\* on referral

## HOSPITAL FACILITIES

Service	The Janeway Site	Health Sciences Centre
Rooming in when children are hospitalized	✓	N/A
Care-by-parent unit	✗	N/A
Hostel service	✓	✓
Educational program <i>e.g. Tutor</i>	✓	✗
Recreational activities <i>e.g. Play program</i>	✓	✗
Special unit for teenagers	✓	✗
Special unit for adults	✗	✓

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 AND MEDICAL COVERAGE

**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 “payer of last resort”, which means that if an individual has coverage under the NLPDP and coverage under a private group health insurance plan, people must first submit receipts for reimbursement 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

Telephone: 709-729-4984

E-mail: [healthinfo@gov.nl.ca](mailto:healthinfo@gov.nl.ca)

## 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:** [AESE@nl.ca](mailto:AESE@nl.ca)

**Medical Transportation Assistance Program (MTAP)** 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.

**Telephone:** 1-877-475-2412

## EDUCATION AND EMPLOYMENT

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

### **Department of Advanced Education, Skills and Labour**

**Telephone:** 709-729-2480  
**Toll free:** 1-800-563-6600  
**E-mail:** [AESE@nl.ca](mailto:AESE@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.

**Telephone:** 709-729-5881  
**Toll free:** 1-888-729-7690  
**E-mail:** [openingdoors@gov.nl.ca](mailto:openingdoors@gov.nl.ca)

**Employment Insurance** is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for in-depth information on employment insurance, eligibility, and specific benefits.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

In addition to the following resource, [visit the Canada-wide mental health and emotional wellness section](#)

- **CHANNAL Peer Support Warm Line:** 1-855-753-2560 or (709) 753-2560
- **Mental Health and Addictions Systems Navigator:** 1-877-999-7589 or (709) 752-3916
- **Provincial Mental Health Crisis Line:** 1-888-737-4668 or (709) 737-4668
- [Strongest Families Institute \(SFI\)](#) is a not-for-profit agency that provides support to families over the phone and internet about children and youth (ages 3-17) behavior difficulties, anxiety, and more.

### Adults

- [Bridge the gApp Adult](#) is a free online resource that provides a searchable service directory for self-help information and local resources for emotional wellness.
- [I CAN \(Conquer Anxiety and Nervousness\) Adult program](#), free for Newfoundland and Labrador residents, supports adults (18-30 years old) by providing telephone and online coaching of life skills to overcome anxiety and cope with major life stressors: 1-866-470-7111

### Youth and Children

- [BreathingRoom](#) is an online self-management program for youth and young adults seeking ways to manage stress, anxiety and depression.
- [Bridge the gApp Youth](#) is a free online resource that provides a searchable service directory for self-help information and local resources for emotional wellness.
- **Crisis Text Line** powered by Kids Help Phone: text "Talk" to 686868

## MEDICAL EQUIPMENT, SUPPLIES AND OXYGEN

Compressors, percussors, nebulizers, glucoscans, oxygen and postural drainage couches are provided through the provincial Department of Health and Community Services' [Special Assistance Program – Medical equipment and supplies](#) 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.

## 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.

## HOME CARE

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:

**Telephone:** 709-729-4984  
**E-mail:** [healthinfo@gov.nl.ca](mailto:healthinfo@gov.nl.ca)

## SOCIAL SUPPORTS

Contact your local [Cystic Fibrosis Canada Chapter](#) or [CF clinic](#) for details of the existing social support network in the area. There are 9 chapters in the Atlantic Region. [Please see the back of this Guide for a listing of all chapters across Canada.](#)

## ADVOCACY

[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 and inclusion.

**Telephone:** 709-722-7011  
**E-mail:** [info@codnl.ca](mailto:info@codnl.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.

**Toll free:** 1-866-753-9860  
**E-mail:** [csc@cscnl.ca](mailto:csc@cscnl.ca)

[Cystic Fibrosis Canada](#) has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or call Cystic Fibrosis Canada at 1-800-378-2233.

**Empower: The Disability 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.

**Telephone:** 709-722-4031  
**Toll free:** 1-866-722-4031  
**Fax:** 709-722-0147  
**E-mail:** [info@empowernl.ca](mailto:info@empowernl.ca)

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

**Telephone:** 709-729-2709  
**Toll free:** 1-800-563-5808  
**Fax:** 709-729-0790  
**E-mail:** [humanrights@gov.nl.ca](mailto:humanrights@gov.nl.ca)

## NEWBORN SCREENING

Newfoundland and Labrador screens newborns for cystic fibrosis. Please contact the [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

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:

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

## TRANSPLANT CENTRES

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.

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

# NOVA SCOTIA RESOURCES

## CF CLINICS

<p><b>I.W.K Health Centre</b> (paediatric)  <b>Nurse Coordinator:</b> Paula Barrett  <b>Telephone:</b> 902-470-8219</p>	<p><b>QE II Health Sciences Centre</b> (adult)  <b>Nurse Coordinator:</b> Fran Gosse  <b>Telephone:</b> 902-473-4024</p>
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**Appendix G** is a list of all the CF clinics with contact information such as addresses and fax numbers included.

## OUTREACH CLINICS:

\*The I.W.K. team travels to Sydney, Nova Scotia; Charlottetown, Prince Edward Island; and Bathurst and Fredericton, New Brunswick, to provide clinic service to patients and families closer to home.

## CLINIC RESOURCES

Health Professional	I.W.K Health Centre	QE II Health Sciences Centre
Physiotherapist	✓	✓
Social Worker	✓	✓
Dietitian	✓	✓
Respirologist/Pulmonologist	✓	✓
Gastroenterologist	*	*
Psychologist/Psychiatrist	*	*
Pharmacist	✓	✓
Endocrinologist	*	*

\*on referral

## HOSPITAL FACILITIES

Service	I.W.K Health Centre	Nova Scotia Health Authority, Halifax Infirmary
Rooming in when children are hospitalized	✓	N/A
Care-by-parent unit	✗	N/A
Hostel service	✓	✓
Educational program <i>e.g. Tutor</i>	✓	✗
Recreational activities <i>e.g. Play program</i>	✓	✗
Special unit for teenagers	✗	✗
Special unit for adults	✗	✓

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.

At the Nova Scotia Health Authority, all CF patients have private rooms.

## DRUG AND MEDICAL COVERAGE

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**

**Telephone:** 902-429-6565

**Toll free:** 1-800-544-6191

## FINANCIAL ASSISTANCE

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

The [Income Assistance \(IA\)](#) program provides financial support with basic needs such as food, rent, utilities, clothing and sometimes also; child care, transportation, and prescription drugs, all for individuals in financial need.



## EDUCATION AND EMPLOYMENT

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

**Telephone:** 902-424-4329

**Department of Labour and Advanced Education** has [career planning](#) and [labour information](#) on programs designed specifically for Nova Scotians, including skills development, self-employment, and employment assistance services.

**Toll free:** 1-877-223-0888

**Entrepreneurs with Disabilities Network (EDN)** has joined [TEAM Work](#) Cooperative as it continues to promote and facilitate entrepreneurship among persons with disabilities.

**Telephone:** 902-422-8900  
**Toll free:** 1-888-576-4444  
**Fax:** 902-422-3992

Social assistance may be available through the Nova Scotia **Department of Community Services, [Employment Support and Income Assistance Program](#)**.

[Out of Province Travel and Accommodation Assistance Policy](#) 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.

**Telephone:** 902-424-7538  
**Toll free:** 1-877-449-5476

[Employment Insurance](#) is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for In-depth information on employment insurance, eligibility, and specific benefits.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

In addition to the following resource, [visit the Canada-wide mental health and emotional wellness section](#)

- The **provincial mental health crisis line** is available 24/7, across the province: 1-888-429-8167 or 902-429-8167
- [Nova Scotia division of the Canadian Mental Health Association](#) provides a list of emotional wellness programs and services.
- [Mental Health Foundation of Nova Scotia](#) lists several regional programs and provincial organizations with a focus on mental health supports for all age groups.
- Individuals seeking mental health and emotional wellness care can refer themselves by contacting the [health authority's service lines](#) for their area.

## Adults

- The [IWK Health Centre](#) provides adults, families and friends throughout the province with specialized mental health and addictions programs and services, available in person or online.

## Youth and Children

- The [IWK Health Centre](#) provides children and adolescents throughout the province with specialized mental health and addictions programs and services, available in person or online.

## MEDICAL EQUIPMENT, SUPPLIES AND OXYGEN

Equipment (such as aerosol machines, nebulizers, facemasks, mouthpiece, oxygen tubing, portable compressors, compressors, PEP equipment, ultrasonic humidifiers, etc.) is provided through the provincial **Medical Services Insurance (MSI)** Program at no cost to individuals with CF. Contact the CF clinic coordinator for information on equipment or servicing.

## 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 are eligible to receive special needs funding for assistance with the cost of a special diet.

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**  
**Telephone:** 902-496-7008  
**Toll free:** 1-800-563-8880  
**E-mail:** [MSI@medavie.ca](mailto:MSI@medavie.ca)

## HOME CARE

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

**Telephone:** 902-424-6090  
**Toll free:** 1-800-225-7225

## SOCIAL SUPPORTS

Caregivers Nova Scotia is an organization that provides a variety of resources for caregivers. They help friends and families find the services, programs, support groups, and advocacy initiatives that they need.

**Toll free:** 1-877-488-7390  
**E-mail:** [info@caregiversNS.org](mailto:info@caregiversNS.org)

Contact your local Cystic Fibrosis Canada Chapter or CF clinic for details of the existing social support network in the area. There are 9 chapters in the Atlantic Region. Please see the back of this Guide for a listing of all chapters across Canada.

## ADVOCACY

Cystic Fibrosis Canada has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or call Cystic Fibrosis Canada at 1-800-378-2233.

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.

**Telephone:** 902-424-4111  
**Toll free:** 1-877-269-7699  
**E-mail:** [hrcinquiries@novascotia.ca](mailto:hrcinquiries@novascotia.ca)

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

**Telephone:** 902-455-6942  
**Toll free:** 1-866-696-7536  
**Fax:** 902-454-4781  
**E-mail:** [nsleo2018@outlook.com](mailto:nsleo2018@outlook.com)

## NEWBORN SCREENING

Nova Scotia screens newborns for cystic fibrosis. Please contact the [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

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:

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

## TRANSPLANT CENTRES

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.

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

# ONTARIO RESOURCES

## CF CLINICS

<p><b>Children’s Hospital of Eastern Ontario (CHEO)</b> (paediatric)  <b>Nurse Coordinator:</b> Joanne Hammel  <b>Telephone:</b> 613-737-7600 x 2214</p>	<p><b>London Health Sciences Centre (LHSC) **</b>          (adult)  <b>Adult Nurse Case Manager:</b> Tracy Gooyers  <b>Telephone:</b> 519-685-8500 x 55186</p>
<p><b>Ottawa General Hospital (OGH)</b>          (adult)  <b>Nurse Coordinator:</b> Ena Gaudet  <b>Telephone:</b> 613-737-8899 x 78100</p>	<p><b>London Health Sciences Centre (LHSC) **</b>          (paediatric)  <b>Paediatric Nurse Nurse Coordinator:</b> Jennifer Itterman  <b>Telephone:</b> 519-685-8500 x 52692</p>
<p><b>Hotel Dieu Hospital (HDH)</b>          (adult/paediatric)  <b>Nurse Coordinator:</b> Lisa Smith  <b>Telephone:</b> 613-544-3400 x 3147</p>	<p><b>Grand River Hospital (KWHC) Kitchener-Waterloo Site</b> (paediatric)  <b>Nurse Coordinator:</b> Arlene Valenta  <b>Telephone:</b> 519-749-6868 x 1</p>
<p><b>The Hospital for Sick Children (HSC) *</b>          (paediatric)  <b>Nurse Practitioner:</b> Kate Gent  <b>Telephone:</b> 416-813-5826          416-813-1500</p>	<p><b>St. Mary’s General Hospital (KWHC) Kitchener site</b> (adult)  <b>Nurse Coordinator:</b> Lori Peterson  <b>Telephone:</b> 519-749-4300 x 3716</p>
<p><b>St. Michael’s Hospital (SMH) *</b>          (adult)  <b>Nurse Coordinator:</b> Sandee Westell  <b>Telephone:</b> 416-864-5409</p>	<p><b>Windsor Regional Hospital (WRH)</b>          (paediatric)  <b>Clinic Coordinators:</b> Sue Grebe,          Michelle Murray  <b>Telephone:</b> 519-254-5577</p>
<p><b>Hamilton Health Sciences Corporation (HSC)</b>          (paediatric)  <b>Nurse Coordinator:</b> Val Carroll  <b>Telephone:</b> 905-521-2100 x 73086</p>	<p><b>Sudbury Regional Hospital (SRH)</b>          (adult/paediatric)  <b>Nurse Coordinator:</b> Sharri-Lynne Zinger  <b>Telephone:</b> 705-522-2200 x 3263</p>
<p><b>Hamilton Health Sciences Corporation (HSC)</b>          (adult)  <b>Nurse Coordinator:</b> Kelly Campbell  <b>Telephone:</b> 905-521-2100 x 75711</p>	

**Appendix G** is a list of all the CF clinics with contact information such as addresses and fax numbers included.

## OUTREACH CLINIC

\*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.

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

## CLINIC RESOURCES

Health Professional	CHEO	OGH	HDH	HSC	SMH	HHSC**		LHSC		KWHC		WRH	SRH
						pead.	adult	pead.	adult	pead.	adult		
Physiotherapist	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Social Worker	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓
Dietitian	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Respirologist/ Pulmonologist	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	*	✓
Gastroenterologist	✓	*	*	✓	✓	*	✗	*	*	*	*	*	*
Psychologist/ Psychiatrist	*	*	*	✓	✓	*	*	*	✓	*	*	✗	*
Pharmacist	✓	✓	*	✓	✓	*	*	*	✓	✓	✓	✓	✓
Endocrinologist	*	*	*	*	✓	*	*	*	*	*	*	*	*
Respiratory Therapist	✓	N/A	✓	N/A	✓	N/A	*	N/A	N/A	✓	✓	N/A	✓

\* on referral

\*\* Pediatric clinic provides Child Life Services

## HOSPITAL FACILITIES

Service	CHEO	OGH	HDH	HSC	SMH	HHSC	LHSC	KWHC	WRH	SRH
Rooming in when children are hospitalized	✓	✓	✓	✓	✗	✓*	✓	✓	✓	✓
Care by parent unit	✓	✓	✓	✓	✗**	✓	✓	✓	✓	✓
Hostel service	✓	✓	✓	✓	✗	✓	✓	✗	✗	✗
Educational program <i>e.g. Tutor</i>	✓	✓	✓	✓	✗	✓	✓	✗	✓	✓
Recreational activities <i>e.g. Play program</i>	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓
Special unit for teenagers	✓	✗	✗	✓	✗	✗	✗	✗**	✓	✗
Special unit for adults	✗	✗	✓	✗	✓	✗	✓	✗	✓	✗

- \* Paediatrics only
- \* All patients receive private rooms as available and as per patients' isolation issues
- \*\* Assessed on a case-by-case basis

Hamilton Health Sciences has a **Ronald McDonald House** accessible to the hospital.

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 kept separate from other patients. At HHSC, CHEO, HDH, SMH, and KWHC, CF patients will not be placed in the same room.

## DRUG AND MEDICAL COVERAGE

**Ontario Drug Benefit Program (ODB)** covers most of the cost of prescription drugs listed in the Formulary. Individuals, who are registered in the Trillium Drug Program, receive professional home care services, are considered eligible for OHIP+, 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 ODB. 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.

**Toll free:** 1-866-532-3161

The [Ontario 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.

**Telephone:** 1-866-532-3161

[Ontario Health Insurance Plan Plus \(OHIP+\)](#) covers the complete costs of drug products that are currently available through the Ontario Drug Benefit Program for individuals 24 years of age and under without private insurance coverage. Certain drugs available through the [Exceptional Access Program](#) may also be covered. At this time, patients who have private insurance coverage must be accessed prior to using OHIP+. You can use the online tool to check medication coverage. All individuals who are eligible for OHIP+ (babies, children and youth age 24 years and under who have OHIP coverage) are automatically enrolled. You can [check medication coverage](#) online.

[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:

**Telephone:** 416-642-3038  
**Toll free:** 1-800-575-5386

## 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.

**Telephone:** 1-800-461-4006  
**Brochure:** [Northern Health Travel Grants \(NHTG\) Program](#)

**Ministry of Children and Youth Services** has a [website](#) 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.

**Telephone:** 1-866-821-7770



**Assistance for Children with Severe Disabilities (ACSD)** Program helps parents with some of the extra costs of caring for a child under 18 years 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 - \$455 per month. Contact your local **regional office** and ask for an application form.

**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 assistance 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.

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.

**Telephone:** 1-866-ONT-TAXS (1-866-668-8297)

**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.

**Telephone:** 905-852-1799 ext. 32

**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.

**Telephone:** 204-772-1899  
**Toll free:** 800-552-6820

## EDUCATION AND EMPLOYMENT

**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.

**Telephone:** 416-326-5656  
**Toll free:** 1-800-387-5656

**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 on a month by month basis. 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, please contact:

**Ministry of Community and Social Services**

**Telephone:** 416-325-5666

**Toll free:** 1-888-789-4199

**Employment Insurance** is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for In-depth information on employment insurance, eligibility, and specific benefits.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

In addition to the following resource, [visit the Canada-wide mental health and emotional wellness section](#)

- [Services](#) for those experiencing anxiety or depression (in Toronto)
- [Crisis resources](#), phone numbers for different cities in Ontario
- [Bounce Back®](#) teaches effective skills to help individuals (aged 15+) overcome symptoms of mild to moderate depression or anxiety, and improve their mental health. Participants can learn skills to help combat unhelpful thinking, manage worry and anxiety, and become more active and assertive.

## MEDICAL EQUIPMENT, SUPPLIES 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

**Telephone:** 416-327-8804

**Toll free:** 1-800-268-6021

## 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). At the Hamilton Health Sciences, patients obtain their nutritional supplements through OMS. At the time, MVW Vitamins are not covered under the formulary and are an out of pocket expense.

### [Speciality Food Shop](#)

**Telephone:** 416-813-5294

At Hamilton Health Sciences, patients obtain their nutritional supplements through Ontario Medical Supply (OMS). At this time, MVW Vitamins **are not covered** under the formulary and are an out of pocket expense. Contact the CF team dietitian to discuss which supplements are covered and recommended.

## HOME CARE

[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.

**Telephone:** 310-2222

## SOCIAL SUPPORTS

Contact your local Cystic Fibrosis Canada Chapter ([Northern & Eastern Ontario](#) which has 8 chapters or [Central and Southwestern Ontario](#) which has 10 chapters) or [CF clinic](#) for details of the existing social support network in the area. [Please see the back of this Guide for a listing of all chapters across Canada.](#)

## ADVOCACY

[ARCH Disability Law Centre](#) provides online resources for individuals with a disability seeking legal information or advice.

**Telephone:** 416-482-8255  
**Toll free:** 1-866-482-2724

[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.

**Telephone:** 416-599-2458  
**E-mail:** [cilt@cilt.ca](mailto:cilt@cilt.ca)

[Cystic Fibrosis Canada](#) has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or call Cystic Fibrosis Canada at 1-800-378-2233.

[Ontario Human Rights Commission](#) investigates and resolves complaints of discrimination, and provides programs, services and resources on a range of topics. The Commission also develops programs of public information and education about human rights.

**Telephone:** 416-326-9511  
**Toll free:** 1-800-387-9080  
**E-mail:** [info@ohrc.on.ca](mailto:info@ohrc.on.ca)

## NEWBORN SCREENING

Ontario screens newborns for cystic fibrosis. Please contact a [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

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

## TRANSPLANT CENTRES

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.

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

**Toronto, Ontario:**

[Toronto General Hospital, University Health Network](#) (adult)

**Telephone:** 416-340-4800 ext. 3807

[The Hospital for Sick Children](#) (paediatric)

**Telephone:** 416-813-2233

# PRINCE EDWARD ISLAND RESOURCES

## CF 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**  
**Nurse Coordinator:** Paula Barrett  
**Telephone:** 902-470-8219

[Appendix G](#) is a list of all the CF clinics with contact information such as addresses and fax numbers included.

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 Nova Scotia Health Authority, Halifax Infirmity (adult services) or I.W.K. Health Centre (paediatric services) in Halifax. Please refer to the Nova Scotia section of this guide for further information regarding these clinics.

## DRUG AND MEDICAL COVERAGE

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 PEI 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

**Telephone:** 902-368-4947  
**Toll free:** 1-877-577-3737

### [Health PEI](#)

**Telephone:** 902-368-6130  
**E-mail:** [healthpei@gov.pe.ca](mailto:healthpei@gov.pe.ca)

## FINANCIAL ASSISTANCE

**Financial Assistance Drug 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 have a PEI health card.

**Telephone:** 902-368-4947  
**Toll free:** 1-877-577-3737

**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.

**AccessAbility Supports**  
**Telephone:** 1-877-569-0546

## EDUCATION AND EMPLOYMENT

**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.

**Telephone:** 902-838-0910  
**Toll free:** 1-877-407-0187

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

**Telephone:** 902-892-9149  
**E-mail:** [peicod@peicod.pe.ca](mailto: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).

**Telephone:** 1-877-491-4766

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**.

**Telephone:** 902-368-4640  
**E-mail:** [studentloan@gov.pe.ca](mailto:studentloan@gov.pe.ca)

**Employment Insurance** is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for In-depth information on employment insurance, eligibility, and specific benefits.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

Please [visit the Canada-wide mental health and emotional wellness section](#).

## MEDICAL EQUIPMENT, SUPPLIES AND OXYGEN

Contact the Respiratory Division at the [Queen Elizabeth Hospital](#) in Charlottetown for information on equipment maintenance and servicing at 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. The following two private companies provide oxygen service:

[Medigas](#)

Telephone: 1-866-446-6302

[VitalAire](#)

Telephone: 1-800-664-6410

## 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 [AccessAbility Supports](#). For others, they may be covered through private insurance.

Telephone: 1-877-569-0546

## HOME CARE

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. For more information, please contact your regional office:



<b>Souris:</b> 902-687-7096	<b>Montague:</b> 902-838-0786	<b>Charlottetown:</b> 902-368-4790
<b>Summerside:</b> 902-888-8440	<b>O’Leary:</b> 902-859-8730	<b>Provincial Home Care Director:</b> 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 for a fee. These costs are generally covered by private insurance.

## SOCIAL SUPPORTS

Contact your local [Cystic Fibrosis Canada Chapter](#) or [CF clinic](#) for details of the existing social support network in the area. There are 9 chapters in the Atlantic Region. [Please see the back of this Guide for a listing of all chapters across Canada.](#)

## ADVOCACY

[Cystic Fibrosis Canada](#) has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or call Cystic Fibrosis Canada at 1-800-378-2233.

**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.

**Telephone:** 902-892-9149  
**E-mail:** [peicod@peicod.pe.ca](mailto: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

**Telephone:** 902-368-4180  
**Toll free:** 1-800-237-5031

## NEWBORN SCREENING

PEI screens newborns for cystic fibrosis. Please contact the [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

Genetic counselling and testing are available on referral through a CF or Family physician/nurse. For more information, please contact the CF clinic.

## TRANSPLANT CENTRES

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.

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

# QUEBEC RESOURCES

## CF CLINICS

<p><b>Centre hospitalier régional de Rimouski (CHRR)</b> (adult/paediatric)  <b>Nurse Coordinator:</b> Geneviève Gagné  <b>Telephone:</b> 418-724-3000 ext. 8768</p>	<p><b>Centre Hospitalier Universitaire(CHU) Mère-Enfant (CHUSJ) Hôpital Sainte-Justine</b> (paediatric)  <b>Nurse Coordinator:</b> Isabelle Tellier                      Manon Caissy  <b>Telephone:</b> 514-345-4931 ext. 6045</p>
<p><b>Centre hospitalier de l'Université Laval (CHUL)</b> (paediatric)  <b>Nurse Coordinator:</b> Manon Roussin  <b>Telephone:</b> 418-656-4141 ext. 47506</p>	<p><b>Centre hospitalier de l'Université de Montréal (CHUM)</b> (adult)  <b>Nurse Coordinator:</b> Yung-Chun Chou                      Alicia Brindle-Tessier  <b>Telephone:</b> 514-890-8000 ext. 15667</p>
<p><b>Institut Universitaire de Cardiologie et de Pneumologie de Québec (IUCPQ)*</b> (adult)  <b>Nurse Coordinator:</b> Ève Routhier  <b>Telephone:</b> 418-656-8711 ext. 3538</p>	<p><b>Centre universitaire de santé McGill (CUSM) Institut Thoracique de Montréal</b> (adult)  <b>Nurse Coordinator:</b> Jade Ostiguy-Robillard  <b>Telephone:</b> 514-934-1934 ext. 32121</p>
<p><b>Centre universitaire de santé de Sherbrooke (CHUS)</b> (adult/paediatric)  <b>Nurse Coordinator:</b> Josée Lessard  <b>Telephone:</b> 819-346-1110 ext. 12820</p>	<p><b>Hôpital de Montréal pour Enfants (HME)*</b> (paediatric)  <b>Nurse Coordinator:</b> Deborah Fertuck  <b>Telephone:</b> 514-412-4400 ext. 22643</p>
<p><b>Centre de santé et de services sociaux de Chicoutimi (CSSSC) - Hôpital de Chicoutimi</b> (adult/paediatric)  <b>Nurse Coordinator:</b> Maryse Bandet  <b>Telephone:</b> 418-541-1037</p>	<p><b>Centre de santé et services sociaux de Rouyn-Noranda (CSSRN)</b> (adult/paediatric)  <b>Nurse Coordinator:</b> Claire Myre  <b>Telephone:</b> 819-762-0995</p>

[Appendix G](#) is a list of all the CF clinics with contact information such as addresses and fax numbers included.

## OUTREACH CLINICS

\*A health care team from CF clinics at *Hôpital de Montréal pour Enfants (HME)* and *Institut Universitaire de Cardiologie et de Pneumologie de Québec (IUCPQ)* participate in outreach clinics in Rouyn-Noranda and Baie-Comeau, Quebec.

# CLINIC RESOURCES

Health Professional	CHRR	CHUL	IUCPQ	CHUS	CSSSC	CHUSJ	CHUM	MCI	MCH	CSSRN
Physiotherapist	✓	✓	✓	✓	✓	✓	***	✓	✓	✓
Social Worker	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓
Dietitian	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Respirologist/ Pulmonologist	✓*	✓	✓	✓	✓*	✓	✓	✓	✓	✓
Gastroenterologist	✓*	***	***	✓	✓***	✓	***	***	✓	***
Psychologist/ Psychiatrist	***	***	***	***	✓	✓	***	***	✓	***
Pharmacist	***	***	***	***	✓***	✓	✗	***	***	***
Endocrinologist	***	***	***	✓	✓^	✓	✓	***	***	***
Respiratory Therapist	✓	✓	✓	***	✓	✓	✓	***	✓	✓
Fertility clinic	✓	N/A	***	✓	✓	✓	***	✓	***	✓

\*\*\* On referral

\* yes adult, no paediatric

\*\* on referral for adult, no paediatric

^ on referral for adult, yes paediatric

^^ no adult, yes paediatric

## HOSPITAL FACILITIES

Service	CHRR	CHUL	IUCPQ	CHUS	CSSSC	CHUSJ	CHUM	MCI	MCH	CSSRN
Rooming in when children are hospitalized	✓	✓	✗	✓	✓ <sup>^^</sup>	✓	✓	✓	✓	✓
Care by parent unit	✓	✓	✓	✗	✓	✓	N/A	N/A	✓	✓*
Hostel service	✓	✓	✓	✗	✗	N/A	✗	✗	✗	✗
Educational program <i>e.g. Tutor</i>	✗	✗	✓	✓	✓	✓	N/A	N/A	✓	✗
Recreational activities <i>e.g. Play program</i>	✓	✓	✗	✓	✗	✓	N/A	N/A	✓	✗
Special unit for teenagers	✗*	✗	✗	✗*	✓	✗	N/A	N/A	✗	✗*
Special unit for adults	✗*	N/A	✓	✓	✓	N/A	✓	✓	N/A	✗*

\* On referral

*All patients are provided private rooms at all institutions.*

*At CHRR, teens and adults are hospitalized in the paediatric department.*

*At CHUS, teens are hospitalized in the paediatric department and the adults are hospitalized in the pneumology department.*

*At CSSRN, the teens and adults are hospitalized in the paediatric department. Additionally, there is possibility of financial aid for accommodations near the hospital.*

## DRUG AND MEDICAL COVERAGE

[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 \$636 depending on net family income (premium adjusted annually on July 1st). 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.

For more information, please visit: [Public Prescription Drug Insurance Plan](#)

Most CF drugs covered by the provincial program are listed on the [List of Medications](#), published periodically by the [Régie de l’assurance maladie](#). Some medications are available to individuals with CF through [médicaments d’exception](#), as a special exception medication, or through [exception patient measure](#), if prescribed by a CF physician.

Telephone: 418-646-4636 (Québec)  
 Telephone: 514-864- 4311 (Montréal)  
 Toll free: 1-800-561-9749

## FINANCIAL ASSISTANCE

### **For adults with CF:**

**Tax credit:** Provincial and Federal tax credits for disabled individuals are available to eligible residents of Quebec. Please see the Canada Revenue Agency section of the Canada-wide resources within this guide for further information.

[Disability Tax Credit Certificate](#) (Federal)  
[Certificate Respecting an Impairment TP-752.0.14-V](#)

**Disability Pension:** 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.

Telephone: 418-643-5185 (Québec)  
 Telephone: 514-873-2433 (Montréal)  
 Toll free: 1-800-463-5185

**Social Assistance and Social Solidarity Programs:** The [Social Assistance and Social Solidarity programs](#) are last-resort financial assistance. The amount of financial assistance given depends on the situation of the person. There are two programs: the Social Assistance Program for a person **with no** severe limited capacity for employment **and** the Social Solidarity Program **for a person with a severe limited capacity for employment**.

**Costs reimbursable to patients who must travel to receive health care and services not available in their area:**

[The Ministère de la Santé et des Services sociaux](#) [Department of Health and Social Services] (French only) grants financial support, in the form of a lump-sum allowance, to patients who must travel outside of their area of residence to receive the care and services required by their health condition. The necessary care and services are not of an urgent nature that would

require immediate hospitalization. The purpose of the lump-sum allowance is to compensate patients for the cost of return travel, as well as expenses incurred during their stay (meals and accommodations). The health care institution in the patient's area of residence is responsible for processing and paying the allowance.

**Tax credit for medical services not available in your area:**

You may be eligible to claim this tax credit if you paid expenses to obtain medical services that were **not available in your area**.

***For parents of a child with CF:***

As parents of a child followed at a CF Clinic, you may be eligible for the following:

**Disability Tax Credit Certificate** Please see the Canada Revenue Agency section of the Canada-wide resources within this guide for further information. Also, speak with a member of the CF clinic team regarding your child's medical eligibility for the tax credit.

**Employment Insurance Compassionate Care Benefits for caregivers and other family members:** please speak with a member of your CF clinic care team about eligibility.

**The Supplement for Handicapped Children** The purpose of the supplement for handicapped children is to provide financial assistance for families to help with the care and education of a handicapped child. Please see the Retraite Quebec website for eligibility criteria and application process. Also, speak with a member of the medical team regarding your child's medical eligibility for the supplement.

The **Maison des greffés Lyna Cyr**, located in Montreal, offers affordable accommodations to people from remote areas of Quebec who are awaiting an organ transplant or returning for their postoperative follow-up. The patient and the person accompanying him/her can find lodging here at an affordable rate.

**Address:** 1989 Sherbrooke Street East, Montreal, Quebec  
H2K 1B8 Canada  
**Telephone:** 514-527-8661  
**E-mail:** [michelineasselin@videotron.ca](mailto:michelineasselin@videotron.ca)

## EDUCATION AND EMPLOYMENT

### **Education:**

**The Loans and Bursaries Program** of Ministère de l'Éducation et de l'Enseignement supérieur enables Québec students with insufficient financial resources to pursue full-time secondary school level vocational training, college or university studies.

**Major Functional Disability:** Under the Loans and Bursaries Program, a major functional disability is a permanent physical handicap. This leads to significant and persistent limitations on the affected person and has an impact on their ability to accomplish daily activities and pursue their education.

If you have a recognized major functional disability and are enrolled in at least 20 course hours a month, you could qualify for the Loans and Bursaries Program, subject to meeting other [eligibility requirements](#) of the program.

In certain cases, while the Program's [general terms and conditions](#) still apply, one can benefit from special measures that are based on needs. If you qualify, you could receive other financial assistance.

**Serious Mental or Physical Health Disorder:** A serious episodic and permanent mental or physical health disorder can temporarily prevent individuals from pursuing full-time studies.

If you are a full-time student and suffer from this problem, which obliges you to temporarily become a part-time student for more than one month, you could still qualify for the Loans and Bursaries Program. Your financial assistance will be paid in the form of loans and bursaries.

**Telephone:** 418 643-3750 (Québec City area)

**Telephone:** 514 864-3557 (Montréal area)

**Telephone:** 418 646-5245 (voice mail) (Outside Canada and the USA)

**Toll free:** 1 877 643-3750 (in Canada and the USA)

### Employment:

There are some 150 [local employment centres \(CLEs\) and services points](#) located throughout the various regions of Quebec that are under the jurisdiction of the Ministère du Travail, de l'Emploi et de la Solidarité sociale [Department of Labour, Employment and Social Solidarity]. Each one offers resources and services for people who need employment and/or last resort financial assistance.

The Ministère du Travail, de l'Emploi et de la Solidarité sociale created the site above, which offers a wide range of information, as well as various services and resources, to provide employment assistance to people with disabilities.

Throughout the various regions of Quebec, there are **organizations specialized in the employability of people with disabilities** that operate in partnership with Emploi-Québec. They have different names, e.g. [Service externe de main-d'œuvre \(SEMO\)](#) [External Workforce Service] or [Service d'aide à l'emploi et de placement en entreprises pour personnes handicapées \(SDEM-SEMO\)](#) [Employment and Work Placement Assistance for People With Disabilities] or [Service spécialisé de main-d'œuvre pour personnes handicapées \(SSMO\)](#) [Specialized Workforce Service for People With Disabilities]. They offer coaching, counselling and job search support services, as well as labour market preparation activities. [Contact your Emploi-Québec local employment centre \(CLE\)](#) or the social worker at your clinic to find out which organization operates in your area.

The **Employment Integration Contract** measure facilitates the hiring and retention of people with disabilities in a standard work environment. In more general terms, it promotes equal access to the labour market for people with disabilities. The measure allows for the reimbursement to the employer of certain expenses required for the integration or retention of people with disabilities. The employer must offer the coaching that the person requires and collaborate in monitoring his/her case.



The financial assistance can take several forms, including:

- a wage subsidy to compensate for the disabled person's lack of productivity and the additional coaching that his/her disabilities require;
- the coverage of certain additional expenses, e.g. to make the workplace accessible or to adapt a workstation for the person who was hired.

Contact your *Emploi-Québec local employment centre (CLE)*.

**Employment Insurance** is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for In-depth information on employment insurance, eligibility, and specific benefits.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

In addition to the following resource, [visit the Canada-wide mental health and emotional wellness section on.](#)

- **AmiQuébec** aims to help individuals dealing with a mental illness and their caregivers, families and/or friends find the appropriate supports. They have a number of free programs and supports that they offer. They can connect individuals to support groups.
- **Mental Health Quebec** provides a list of contact information for various mental health organizations of all age groups. They can connect individuals to local support groups.
- **Revivre** provides supports for anxiety, depression and bipolar disorder. Their site has a lot of information, including suggested steps to take to get the help needed. They also run various support groups.

## MEDICAL EQUIPMENT, SUPPLIES AND OXYGEN

Oxygen, compressors and nebulizers are available via the local community service centres (CLSCs) or health and social services centres (CSSSs) if the person is not covered by a private insurance. Individuals with private insurance generally have a percentage of the cost covered by the insurance company according to their policy. Equipment such as percussors can be available on short-term loans from some CF clinics or via a private insurance. Contact the local nurse coordinator for details on availability and servicing.

## NUTRITIONAL SUPPLEMENTS

The **RAMQ** covers certain commercial oral supplements and the majority of enteral supplements. Feeding tubes and pumps required for enteral nutrition are covered by the Ministerial Enteral

Nutrition Program. Feeding tubes are also generally covered by private insurers. Pumps are usually available at any pharmaceutical company that provides nutritional supplements. Contact the nutritionist at your CF clinic for further information.

## HOME CARE

Home care is provided through local community service centers (centre local de services communautaires, CLSCs), or health and social services centers (centre de santé et de services sociaux, CSSSs) to all Quebec residents.

Home care support services are intended to help people who are losing their autonomy or are unable to get around due to health problems or a physical or mental impairment. They are available to avoid or reduce hospital stays and make it easier for people to return home. All of the services are provided through the public network, at home or in clinics, local community service centres following an illness or surgery. A personal care plan defining the services the person need in order to stay in his or her home is drawn up following a professional assessment. The plan sets out the services that are required for the person to remain at home. Certain services are provided to the caregivers of these persons. Most of those services are free of charge.

### Services include:

- professional care (Ex. Nurse, Physiotherapist) and services;
- home help;
- services for caregivers;
- technical support.

For more information on homecare services, please visit: [Home Care Support](#)

## SOCIAL SUPPORTS

Contact your local [Cystic Fibrosis Canada Chapter](#) or [CF clinic](#) for details of the existing social support network in the area. There are 10 chapters in the Quebec Region. [Please see the back of this Guide for a listing of all chapters across Canada.](#)

### **Cystic Fibrosis Canada – Montreal Regional Office**

**Telephone:** 514-877-6161

**Toll free:** 1-800-363-7711

### **Cystic Fibrosis Canada – Est du Québec Regional Office**

**Telephone** 418-653-2086

**Toll free:** 1-877-653-2086

[Office des personnes handicapées du Québec \(OPHQ\)](#) is a government organization that works to promote the social participation and inclusion of people living with disabilities. They can help direct people to government-related supports based on need. OPHQ has also published a few guides, including a [guide to programs for people with a disabilities, their families and caregivers.](#)

**Telephone:** 1-800-567-1465  
**Toll free:** 1-800-567-1477  
**Fax:** 1-819-475-8753  
**E-mail:** [info@ophq.gouv.qc.ca](mailto:info@ophq.gouv.qc.ca)

**Vivre avec la fibrose kystique** is an organization that works to promote quality of life for people living with Cystic Fibrosis. They have a number of programs available to people living with cystic fibrosis and their families. *(Their website and staff are bilingual, however, all their application forms for assistance are only available in French)*

**Telephone:** 514-288-3157 (Montréal and the surroundings)  
**Toll free:** 1-800-315-3157  
**E-mail:** [info@vivreaveclafk.com](mailto:info@vivreaveclafk.com)

The **Fondation l'air d'aller** is a non-profit charity organization whose mission is to raise funds in order to redistribute them in various forms: scholarships, grocery vouchers, free appointments with a psychologist and material assistance. This site is available only in French, but the people in charge are bilingual.

**Telephone:** 514-476-6934 or 514-919-2060  
**E-mail:** [fondationlairdaller@videotron.ca](mailto:fondationlairdaller@videotron.ca)

**Tousse ensemble** is a support system for families with children or adults living with cystic fibrosis. They provide support through informative or referral services and also develop informative kits on various topics that are available for download from their website (only in French).

**S'unir pour guérir** is a private Facebook group that unites families with children or adults living with cystic fibrosis.

**Hôpital Ste-Justine** has a page on their website that provides various **informative brochures** and documents on cystic fibrosis and other topics such as, cystic fibrosis related diabetes (CFRD), sweat test, bronchoscopy, and more. *(Brochures available in French only)*

## ADVOCACY

**Cystic Fibrosis Canada** has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or call Cystic Fibrosis Canada at 1-800-378-2233.

**Commission des droits de la personne et des droits de la jeunesse (CDPDJ)** Quebec, is a commission that works to foster equality and reduce discrimination through public education of your rights, defending your rights, and employer responsibilities.

**Telephone:** 514-873-5146  
**Toll free:** 1-800-361-6477  
**E-mail:** [information@cdpdj.qc.ca](mailto:information@cdpdj.qc.ca)

**Office des personnes handicapées du Québec (OPHQ)** individually assesses and works with people with disabilities and their families to help meet their needs in terms of school, work and social integration. The office also refers individuals and families to the most appropriate resources. They provide information on your rights and remedies.

**Telephone:** 1-800-567-1465  
**Toll free:** 1-800-567-1477  
**Fax:** 1-819-475-8753  
**E-mail:** [info@ophq.gouv.qc.ca](mailto:info@ophq.gouv.qc.ca)

**Vivre avec la fibrosekystique** is an organization that works to promote quality of life for people living with Cystic Fibrosis. They have a number of programs available to people living with cystic fibrosis and their families. *(Their website and staff are bilingual, however, all their application forms for assistance are only available in French)*

**Telephone:** 514 288-3157 (Montreal and the surroundings)  
**Toll free:** 1 800 315-3157  
**E-mail:** [info@vivreaveclafk.com](mailto:info@vivreaveclafk.com)

## NEWBORN SCREENING

Quebec screens newborns for cystic fibrosis. Please contact a [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

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 at the Montreal University Health Center (MUHC). Please see the nurse coordinator and/or CF physician for further information.

## TRANSPLANT CENTRE

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.

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

**Montréal, Québec :**  
**[Centre hospitalier de l'Université de Montréal](#)** (adult/paediatric)  
**Telephone:** 514-890-8000

# SASKATCHEWAN RESOURCES

## CF CLINICS

<p><b>Regina General Hospital</b> (paediatric)  <b>Nurse Coordinator:</b> Tess Trenker  <b>Telephone:</b> 306-766-4289</p>	<p><b>Royal University Hospital</b> (adult)  <b>Nurse Coordinator:</b> Niki Afseth  <b>Telephone:</b> 306-655-6781  <b>Email:</b> <a href="mailto:adultCFclinic@saskhealthauthority.ca">adultCFclinic@saskhealthauthority.ca</a></p>
<p><b>Royal University Hospital</b> (paediatric)  <b>Nurse Coordinator:</b> Lorna Kosteniuk  <b>Telephone:</b> 306-655-2948</p>	

**Appendix G** is a list of all the CF clinics with contact information such as addresses and fax numbers included.

## CLINIC RESOURCES

Health Professional	Regina General Hospital	Royal University Hospital (adult and paediatric)
Physiotherapist	✓	✓
Social Worker	✓	✓
Dietitian	✓	✓
Respirologist/Pulmonologist	*	✓
Gastroenterologist	*	*
Psychologist/Psychiatrist	*	*
Pharmacist	*	✓
Endocrinologist	*	*
Transplant	*	*

\* on referral

## HOSPITAL FACILITIES

Service	Regina General Hospital	Royal University Hospital (Paediatric)	Royal University Hospital (Adult)
Rooming in when children are hospitalized	✓	✓	N/A
Care-by-parent unit	✗	✓	N/A
Hostel service	✓	✗	✗
Educational program <i>e.g. Tutor</i>	✓	✓	✗
Recreational activities <i>e.g. Play program</i>	✓	✓	✗
Special unit for teenagers	✗	✗	✗
Special unit for adults	✓	✗	✓

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

Please note that there is a new children's hospital opening in Saskatoon in 2019, adjacent to Royal University Hospital, which will serve paediatric patients in the province.

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

## DRUG AND MEDICAL COVERAGE

[Saskatchewan Aids to Independent Living Program \(SAIL\)](#) provides benefits to assist people with disabilities and certain chronic health conditions, including cystic fibrosis.

**Telephone:** 306-787-7121

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. 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).

**Telephone:** 306-787-8744  
**Toll free:** 1-800-667-2549

## FINANCIAL ASSISTANCE

Individuals with CF may qualify for financial assistance as persons with disabilities. **In addition to the financial assistance opportunities listed in the Canada-wide section**, please see the CF clinic social worker for 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, medical travel, etc. 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.

**Telephone:** 306-244-6400 Ext. 1

## EDUCATION AND EMPLOYMENT

**Workforce Development for Persons with Disabilities Program (WFD-PD)** 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.

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

**Telephone:** 1-800-597-8278

**Employment Insurance** is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, family caregiver benefits, and self-employed benefits. Visit the employment insurance website for In-depth information on employment insurance, eligibility, and specific benefits.

## MENTAL HEALTH AND EMOTIONAL WELLNESS

In cases of emergency, or if someone is at risk for harming themselves or someone else, please call **911** or visit your nearest Emergency department.

In addition to the following resource, [visit the Canada-wide mental health and emotional wellness section on.](#)

## MEDICAL EQUIPMENT, SUPPLIES 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. Pediatric Heated Humidifier and Flow Source Generators (AIRVO) are covered.

There are several types of airway clearance devices as options for physiotherapy treatment. Most devices are not covered under any program. These devices include percussors, PEP, vest, acapella, etc. Some private insurance companies may cover these.

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, or contact [SaskAbilities](#) at 306-664-6646.

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 cited above.

## NUTRITIONAL SUPPLEMENTS

*For information on nutritional supplements, please contact the CF clinic.*

## HOME CARE

Physiotherapy, nursing, occupational therapy, 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: [Home care services.](#)

## SOCIAL SUPPORTS

Contact your local [Cystic Fibrosis Canada Chapter](#) or [CF clinic](#) for details of the existing social support network in the area. There are 4 chapters in the Prairies Region. [Please see the back of this Guide for a listing of all chapters across Canada.](#)



## ADVOCACY

[Cystic Fibrosis Canada](#) has a national advocacy program that trains and supports people with cystic fibrosis, their caregivers, and families to advocate for access to medicines, social supports and quality CF care. For more information about the advocacy program, contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca) or call Cystic Fibrosis Canada at 1-800-378-2233.

[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.

**Telephone:** 306-933-5952 or 1-800-667-9249

[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.

**Telephone:** 306-695-3111

[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.

**Telephone:** 1-800-322-7221

## NEWBORN SCREENING

Saskatchewan screens newborns for cystic fibrosis. Please contact a [CF clinic](#) for further information.

## GENETIC COUNSELLING AND TESTING

Genetic counselling is available in Saskatchewan through the [Medical Genetics Clinic](#). Individuals must be referred to the clinic. There is also a genetic counsellor available at the Royal University Hospital CF clinics for individuals with CF and their families.

**Telephone:** 306-655-1692

## TRANSPLANT CENTRES

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.

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

# TIPS AND BEST PRACTICES FOR ACCESS TO SUPPORTS

## TRANSITIONING CLINICS AND/OR INTERPROVINCIAL TRANSITIONS

Patients with CF can move from clinic to clinic for a variety of reasons; adulthood, education, employment, additional support, etc. Prior to leaving your current clinic, it is helpful to become familiar with the differences in coverage that may occur due to age, provincial health care programs, available resources, and program eligibility criteria. Your CF team can assist you in navigating and managing the differences. Overall, there are some key points that can promote a smooth transition:

- 1) Speak to your clinic team about transitioning clinics with as much advance notice as possible. If you are changing provinces, it is often helpful to speak with the social worker at the new clinic you will be attending.
- 2) Ensure that you have a stock of medications, enzymes, vitamins, supplies, etc. (3 months is ideal) before leaving your clinic.
- 3) Often times, you can access appropriate application forms online (provincial health care plans, health insurance plans, program applications). It may be helpful to review these forms beforehand to determine what identification or supporting documents are required with the application.
- 4) Apply for your respective provincial health care insurance plan within 3 months of moving provinces. Carry your health care card from your previous province or territory and present it when accessing insured health services.
- 5) Do not delay in applying for health care benefits or your provincial health care insurance plan. There are often timelines that must be met. If these timelines are missed, wait periods are often enforced resulting in gaps in coverage.

## FAMILY PLANNING

Canada has one of the highest median survival rates in the world for patients who have CF. As such, they are experiencing greater life stages including having families, biologically and/or through adoption. Some individuals will require assistance in fulfilling this wish. To access biological assistance, your CF team will refer you to a public or private fertility clinic. However, prior to embarking upon this journey, it will be important to undergo genetic testing to determine CF diagnoses or CF carriers. Your CF clinic can assist with genetic testing. Although some investigations and medications are covered under your provincial health plan or through employer benefits, there are generally considerable costs associated with fertility medications and services. The Fertility Clinic team will partner with you in determining a course of treatment that is best suited to your situation. Treatments courses can include: intrauterine insemination (IUI), percutaneous epididymal sperm aspiration (PESA), intracytoplasmic sperm injection (ICSI), in vitro fertilization (IVF), egg donor, sperm donor, and surrogacy.

Creating or expanding a family requires careful consideration for you, your significant other, baby, and your supports. Discussion and planning pregnancy with your CF clinic will be important to provide support and care to ensure overall health is optimized pre and postnatally.

### *If you are unsure about something, ask!*

Your CF team is there to help you. You have a whole team of experts to assist you with things such as access to resources, medication coverage, treatment options, and navigating the healthcare system. They can help you find the information you are seeking, are able to provide valuable guidance, and can help direct and support you on your CF journey.

## INFORMATION REQUESTS AND REFERRALS SERVICE

Cystic Fibrosis Canada offers an information request and referral service to help the CF community navigate government and community-based resources. This bilingual service assists with inquiries typically related to the following topics: CF diagnosis, CF facts, CF health, clinical, education, employment, finances, government relations and advocacy, global affairs, and research. You can contact Eunice, Coordinator, Community Relations and Resources, with any queries pertaining to resources and disability supports.

**Telephone:** 416-485-9149 ext. 403  
**Toll free:** 1-800-378-2233 ext. 403  
**E-mail:** [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca)

# ADDITIONAL CF RESOURCES

[Cystic Fibrosis Australia](#)

[Cystic Fibrosis Canada - CF Resources](#)

[Cystic Fibrosis Foundation](#)

[Cystic Fibrosis Trust – United Kingdom](#)

[Exercise videos specifically for people with CF](#)

[Fertility and Family Planning webinar series](#)

[Info RX for CF \(Appendix F\)](#)

[Mayo Clinic – Cystic Fibrosis](#)

[MyHealth.Alberta.ca – Cystic Fibrosis](#)

[The Canadian Cystic Fibrosis Registry](#)

[Tips for CF Parents](#)

# CF CANADA CHAPTERS

In addition to the information below, you can [find your nearest chapter](#) using the CF Canada website.

## ATLANTIC REGION

The Atlantic Region of Cystic Fibrosis Canada includes Newfoundland and Labrador, New Brunswick, Nova Scotia and Prince Edward Island.

<b>ATLANTIC REGION</b> Brittany Smith Telephone: (902) 425-2462 ext. 2 Email: <a href="mailto:bsmith@cysticfibrosis.ca">bsmith@cysticfibrosis.ca</a>	<b>PEI</b> Ray Carmichael Email: <a href="mailto:raycar3@hotmail.com">raycar3@hotmail.com</a>
<b>CAPE BRETON ISLAND</b> Atlantic Region Telephone: (902) 425-2462 Email: <a href="mailto:atlanticregion@cysticfibrosis.ca">atlanticregion@cysticfibrosis.ca</a>	<b>SAINT JOHN</b> Tiffany Wilson Email: <a href="mailto:forevertiffygirl@hotmail.com">forevertiffygirl@hotmail.com</a>
<b>FREDERICTON &amp; NORTHWEST VALLEY</b> Lee Burry Email: <a href="mailto:leeburrycf@gmail.com">leeburrycf@gmail.com</a>	<b>SCOTIA</b> Stephen Vigneau Telephone: 902-425-2462 Email: <a href="mailto:stephenmvigneau@gmail.com">stephenmvigneau@gmail.com</a>
<b>MONCTON</b> Dave Watson Telephone: 506-852-7188 Email: <a href="mailto:davidwatson3591@gmail.com">davidwatson3591@gmail.com</a>	<b>SOUTH WEST NOVA &amp; VALLEY</b> Agatha Bourassa Email: <a href="mailto:timvallillee@hotmail.com">timvallillee@hotmail.com</a>
<b>NEWFOUNDLAND &amp; LABRADOR</b> John Bennett Telephone: 709-749-7525 Email: <a href="mailto:jbennett@cysticfibrosis.ca">jbennett@cysticfibrosis.ca</a>	

## ONTARIO REGION

The Ontario Northern & Eastern Region of Cystic Fibrosis Canada includes North Bay, Sault Ste. Marie, Sudbury, Thunder Bay, Cornwall, Kingston, Ottawa and Peterborough.

The Central & Southwestern Ontario Region of Cystic Fibrosis Canada includes chapters that are located from Windsor-Essex to the west, Durham Region to the east, Niagara to the south and the Muskokas to the north.

## ONTARIO NORTHERN & EASTERN REGION

<b>CORNWALL</b> Monika Petridis Telephone: 613-482-7912 x 101 Email: <a href="mailto:mpetridis@cysticfibrosis.ca">mpetridis@cysticfibrosis.ca</a>	<b>PETERBOROUGH</b> Pam Grady Telephone: 705-652-1525 Email: <a href="mailto:pamgrady2012@gmail.com">pamgrady2012@gmail.com</a>
<b>KINGSTON</b> Monika Petridis Telephone: 613-482-7912 x 101 Email: <a href="mailto:mpetridis@cysticfibrosis.ca">mpetridis@cysticfibrosis.ca</a>	<b>SAULT STE. MARIE</b> Frieda Labelle Telephone: 705-782-0603 Email: 705-782-0603
<b>NORTH BAY</b> Paige Shemilt Telephone: 705-499-7629 Email: <a href="mailto:pshemilt@gmail.com">pshemilt@gmail.com</a>	<b>SUDBURY</b> Chantal Filion Telephone: 705-822-1713 Email: <a href="mailto:chantilion@gmail.com">chantilion@gmail.com</a>
<b>OTTAWA</b> Monika Petridis Telephone: 613-482-7912 x 101 Email: <a href="mailto:mpetridis@cysticfibrosis.ca">mpetridis@cysticfibrosis.ca</a>	<b>THUNDER BAY</b> Barb Thomson Telephone: 807-345-9821 Email: <a href="mailto:barbthomson@tbaytel.net">barbthomson@tbaytel.net</a>

## CENTRAL & SOUTHWESTERN ONTARIO REGION

<b>DURHAM REGION</b> Deb Mattson Telephone: 289-928-7322 Email: <a href="mailto:anais4360@gmail.com">anais4360@gmail.com</a>	<b>KITCHENER-WATERLOO</b> Stephanie Fyers Telephone: 519-880-4409 Email: <a href="mailto:sfryers@live.ca">sfryers@live.ca</a>
<b>ESSEX-KENT</b> Jessica Fazio Telephone: 519-328-5408 Email: <a href="mailto:jess.fazio13@gmail.com">jess.fazio13@gmail.com</a>	<b>LONDON</b> Heather Coghill Telephone: 519-282-5288 Email: <a href="mailto:hcoghill@gmail.com">hcoghill@gmail.com</a>
<b>PEEL</b> Mark Maramieri Telephone: 416-938-6604 Email: <a href="mailto:mark.maramieri@gmail.com">mark.maramieri@gmail.com</a>	<b>NIAGARA</b> Gary Donovan Telephone: 416-726-9742 Email: <a href="mailto:gardon502@yahoo.ca">gardon502@yahoo.ca</a>
<b>HAMILTON</b> Tammy Strong Telephone: 905-572-0472 Email: <a href="mailto:hamiltonchapter@cysticfibrosis.ca">hamiltonchapter@cysticfibrosis.ca</a>	<b>SARNIA LAMBTON</b> Tara Bourque Telephone: 226-932-2543 Email: <a href="mailto:tmbourque4@gmail.com">tmbourque4@gmail.com</a>
<b>HURON OXFORD PERTH</b> Donna Yundt Telephone: 226-927-7032   519-347-2581 Email: <a href="mailto:dyundt@hdc.on.ca">dyundt@hdc.on.ca</a>	<b>TORONTO &amp; DISTRICT</b> Jack Segal Email: <a href="mailto:segaljack@hotmail.com">segaljack@hotmail.com</a>

## PRAIRIES REGION

The Prairies Region of Cystic Fibrosis Canada includes North Saskatchewan, South Saskatchewan and Winnipeg.

<b>CYSTIC FIBROSIS CANADA PRAIRIES REGION</b> Andrea Pratt McDowell Telephone: 204-943-7472 Email: <a href="mailto:apratt@cysticfibrosis.ca">apratt@cysticfibrosis.ca</a>	<b>SOUTH SASKATCHEWAN</b> Cara and Mike Weger Telephone: 306-861-6713 Email: <a href="mailto:southsaskcf@sasktel.net">southsaskcf@sasktel.net</a>
<b>NORTH SASKATCHEWAN</b> Kimberly Evans Telephone: 306-690-8826 Email: <a href="mailto:northsaskcf@gmail.com">northsaskcf@gmail.com</a>	<b>WINNIPEG</b> Sheralin Spring Telephone: 204-509-4725 Email: <a href="mailto:sheralin.brigham@gmail.com">sheralin.brigham@gmail.com</a>

## QUÉBEC REGION

The Quebec Region of Cystic Fibrosis Canada includes chapters across Quebec.

<b>BAS ST-LAURENT/GASPÉSIE</b> Telephone: 1-877-653-2086	<b>MAURICIE/CENTRE-DU-QUÉBEC</b> Lisette Tremblay Telephone: 1-800-363-7711
<b>CÔTE NORD</b> Sophie Girard Telephone: 1-877-653-2086	<b>MONTRÉAL</b> Élise Robert Telephone: 1-800-363-7711
<b>CHARLEVOIX OUEST</b> Sylvain Lajoie Telephone: 1-877-653-2086	<b>OUTAOUAIS</b> Daniel Leblanc Telephone: 1-800-363-7711
<b>ESTRIE</b> Manon Francoeur Telephone: 1-800-363-7711	<b>QUÉBEC</b> Telephone: 1-877-653-2086
<b>LA MALBAIE</b> Dorothée Girard Telephone: 1-877-653-2086	<b>SAGUENAY</b> Andrée-Anne Guay Telephone: 1-877-653-2086

## WESTERN CANADA REGION

The Western Region of Cystic Fibrosis Canada includes British Columbia, Alberta and the Yukon Territory

<b>CALGARY &amp; SOUTHERN ALBERTA</b> Jeanette Demers-Weir Telephone: 403-266-5295 Email: <a href="mailto:jdemers-weir@cysticfibrosis.ca">jdemers-weir@cysticfibrosis.ca</a>	<b>PRINCE GEORGE</b> Lesley Girard Telephone: 250-561-2129 Email: <a href="mailto:rnlgirard@hotmail.com">rnlgirard@hotmail.com</a>
<b>CAMPBELL RIVER</b> Jo-Ann Wallis Telephone: 250-923-4992 Email: <a href="mailto:mustangsally45@hotmail.com">mustangsally45@hotmail.com</a>	<b>RED DEER &amp; CENTRAL ALBERTA</b> Kelly Tibbets Telephone: 403-266-5295 Email: <a href="mailto:CFcentralalberta@gmail.com">CFcentralalberta@gmail.com</a>
<b>EDMONTON &amp; NORTHERN ALBERTA</b> Kelvin Van Dasselaar Telephone: 780-466-2265 Email: <a href="mailto:ABinfo@cysticfibrosis.ca">ABinfo@cysticfibrosis.ca</a>	<b>VANCOUVER &amp; LOWER MAINLAND</b> Robert Deane Telephone: 604-436-1158 Email: <a href="mailto:rdeane@blg.com">rdeane@blg.com</a>
<b>KAMLOOPS</b> Matt Robinson Telephone: 250-320-6487 Email: <a href="mailto:cfkamloops@hotmail.com">cfkamloops@hotmail.com</a>	<b>VICTORIA</b> Lynne Rozenboom Telephone: 604-317-3566 Email: <a href="mailto:lrozenboom@cysticfibrosis.ca">lrozenboom@cysticfibrosis.ca</a>
<b>NANAIMO</b> Joy Nikirk Email: <a href="mailto:rjnikirk@shaw.ca">rjnikirk@shaw.ca</a>	<b>YUKON</b> Amy Labonte Telephone: 867-336-2655 Email: <a href="mailto:cfyukon@hotmail.com">cfyukon@hotmail.com</a>
<b>OKANAGAN VALLEY</b> Jodie Lynn Lemke Telephone: 1-250-486-0844 Email: <a href="mailto:hello@jodielynn.ca">hello@jodielynn.ca</a>	



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# APPENDIX A

## ALBERTA WORKS EMERGENCY PRESCRIPTION(S)/DRUG

Provides medication coverage that commences on the first day of the month or when the application is accepted, and ends on the last day of the month. Further information on Emergency Prescription(s)/Drug benefit and detailed instructions on how to apply can be found [here](#).

- 1) For a more efficient process, have an idea of the amount of funds you have in your bank account, and the name and contact information of your preferred pharmacy. Emergency Prescription(s)/Drug coverage will only be issued to one pharmacy, as coverage is non-transferable, so choose an establishment that is most convenient for you.
- 2) Applications for Emergency Prescription(s)/Drugs can be made through fax, telephone, or walk-in at any Alberta Works office; by the applicant, or the applicant and a third party such as your CF Clinic.
- 3) Emergency Prescription(s)/Drug coverage is intended for an immediate, short-lived need. Should you require more ongoing assistance, please refer to the steps for either Alberta Works Income Support or Alberta Adult Health Benefit.

# APPENDIX B

## ALBERTA ADULT HEALTH BENEFIT

Alberta Adult Health Benefit is a provincial program for low income Albertans that provides coverage for prescription medications, vitamins, diabetic supplies, emergency ambulance, dental services, and optical services. Unlike Alberta Works, Alberta Adult Health Benefit services are operated out of one central office located in Edmonton. An application form or frequently asked questions can be found [here](#).

- 1) File your taxes with an accounting service. Alberta Adult Health Benefit requires verification of income, and this information is obtained through Canada Revenue Agency.
- 2) Print off an [application](#) for Alberta Adult Health Benefit from
- 3) Follow the instructions on how to complete the application. Sections that do not pertain to your situation can be marked as **N/A**. Ensure you have signed and dated the sections **My Declaration and Consent for Canada Revenue Agency**.
- 4) If possible, keep a copy of your application for your records. Mail your completed application form to:

**Address:** Alberta Human Services  
Health Benefits Contact Centre  
PO Box 2222 Station Main  
Edmonton, AB T5J 5H3

- 5) Alternatively, applications can be faxed to: (780) 415-8386 in Edmonton, or 1-855-415-8386 toll-free outside of Edmonton.
- 6) Ensure that your taxes are filed each year while on this program, as they will verify income on a yearly basis. Failure to do so will result in a lapse of benefits.

# APPENDIX C

## ASSURED INCOME FOR THE SEVERELY HANDICAPPED (AISH)

It is worthy to highlight that the eligibility for province-based disability benefits varies from province to province. Because you were eligible for and received disability benefits in one province, does not translate that you will automatically be eligible for and receive disability benefits in another province. In Alberta, AISH provides disabled adults with financial and/or health care benefits. Qualification must meet the financial and disability criteria set out by the AISH program. AISH recognizes that disability is complex. AISH assesses disability based on physical, mental, or a combination of both components. Disability is defined as prolonged, typically extending beyond 1 year. As such, it is important to discuss with your CF team the appropriateness of AISH for your situation. Please visit [AISH](#) for more information, including [how to apply](#).

- 1) Please file your taxes with an accounting service. AISH requires verification of income, and this information is obtained through Canada Revenue Agency.
- 2) AISH Applications Part A can be completed online or on paper. Be sure to include how your cystic fibrosis: affects your ability to work, impacts your activities of daily living, the treatment burden of maintaining your level of function, and any other information you would like to convey to AISH when they consider your application.
- 3) Have your physician complete Part B – Medical Report.
- 4) Once both sections have been completed, submit the 2 sections along with all supporting documents as outlined on the Application Checklist Instructions to the AISH office nearest you. Ensure that you have a copy of your entire application package for your records. A list of offices can be found [here](#)
- 5) The length of time for the application process varies, but currently averages about 6 months.

# APPENDIX D

## ALBERTA WORKS INCOME SUPPORT

Alberta Works is a provincial program that provides emergent support for low income Albertans having difficulty meeting their basic needs like food, clothing and shelter. This resource includes income support, health benefits, and assistance and training to find employment. Eligibility for Alberta Works is determined by your assets and ability to return to work. You will need to visit an Alberta Works office, and be assessed by an Intake Worker.

- 1) File your taxes with an accounting service. Alberta Works requires verification of income, and this information is obtained through Canada Revenue Agency.
- 2) Acquire a copy of 3 months of your most recent bank statement. This can be done through internet banking, or by visiting your local bank branch. Alberta Works requires verification of your most recent income.
- 3) If possible obtain a letter from your Cystic Fibrosis clinic, outlining your current situation, current health status, list of medications, and name and contact information of your dispensing pharmacy. This letter can support your application for Alberta Works, but is not crucial for your application.
- 4) To save time, you may complete an Income for Support Application prior to visiting an office. The application can be found [online](#).
- 5) You may also choose to complete a [Direct Deposit form](#) beforehand.
- 6) There are [6 Alberta Works Centres in Calgary](#). Choose an office that is most convenient for you to visit; the office where you apply for Alberta Works is where your file will be held.
- 7) Proceed to the office that you have chosen for your intake assessment. Arrive as early as possible as service is provided on a first come first served basis. A limited number of clients are seen each day. It is recommended that you arrive prior to the office opening as waiting lines regularly form before then. Expect to wait for a period of time so plan your visit accordingly. You may need to bring nourishment, something to drink, medications and/or enzymes.
- 8) Present your 3 month bank statement and the letter from your CF clinic if you have obtained one to the Alberta Works Intake worker. Provide the Intake worker with any information s/he may need to determine your eligibility for Alberta Works benefits. You may be asked to return to the office at a later scheduled time to provide any outstanding information that affects your eligibility.
- 9) Should you be accepted for Alberta Works benefits, coverage is intended to begin very promptly. Should you ever experience a lapse in coverage, it is imperative that you contact your Alberta Works worker or Alberta Works group to determine why coverage has been interrupted. If you do not know who your Alberta Works worker is, please contact the office where your file is held and the receptionist can direct you accordingly.

# APPENDIX E

## EMPLOYMENT INSURANCE

Employment Insurance is a federal program that provides temporary financial benefits to Canadians who are unable to work due to a variety of reasons. Categories of employment insurance include: regular benefits, sickness benefits, maternity and parental benefits, compassionate care benefits, benefits for parents of critically ill children, and self-employed benefits. In-depth information on employment insurance, eligibility, and specific benefits can be found [here](#).

- 1) Applications for Employment Insurance are all completed online. You can access the application at home, or by visiting any Service Canada office and completing the application at one of the Internet kiosks.
- 2) Before beginning your application, ensure that you have gathered important information beforehand. Information such as, social insurance number, mother's maiden name, address and contact information of your employer(s), start date(s) of employment, last day worked, and rate of pay or salary. Although you may pause or return to your application at a later time, having this information in advance will quicken the process.
- 3) The online application can be accessed [here](#). Once you have read all the information, proceed to **"Start application"**.
- 4) Once you have completed your application, keep your confirmation number in a safe place or print a copy of your application for your records.



## Info Rx

## Cystic Fibrosis

Cystic Fibrosis is a genetic disease that mainly impacts the lung and digestive system. Those affected produce thick sticky mucus that can clog the lungs, stomach, intestines, liver, pancreas, and reproductive organs.

**Borrow these books from the FCRC or check your local library!**

### **Cystic Fibrosis: A Guide for Patient and Family**

*David M. Orenstein, Jonathan E. Spahr, Daniel J. Weiner*

This all-encompassing guide provides practical advice for managing cystic fibrosis.

### **Parenting Children with Health Issues: Essential Tools, Tips, and Tactics for Raising Kids with Chronic Illness & Medical Conditions**

*Foster W. Cline and Lisa C. Greene*

Cline and Greene have created this guide to help parents through the struggles of raising a child with a chronic condition.

### **Cystic Fibrosis: The Ultimate Teen Guide (It Happened to Me)**

*Melanie Ann Apel*

Written for teens with input from real teens, this book mixes research and personal experience to give teens all the information they need to manage a life with CF.

### **Sixty-Five Roses: A Sister's Memoir**

*Heather Summerhayes Cariou*

In her memoir, Cariou shares the experiences she had growing up with her sister, who had cystic fibrosis.

### **The Power of Two: A Twin Triumph over Cystic Fibrosis**

*Isabel Stenzel Byrnes and Anabel Stenzel*

Twins Isabel and Anabel were both diagnosed with cystic fibrosis. Their story and the impact on themselves and loved ones is portrayed in this book.



Additional resources available [fcr.ca/ahs.ca/rx/cystic-fibrosis](https://fcr.ca/ahs.ca/rx/cystic-fibrosis)

### **Alex: The Life of a Child**

*Frank Deford*

Frank Deford shares his daughter Alex's story of cystic fibrosis from a father's perspective.

### **Little Brave Ones: For Children Who Battle Cystic Fibrosis**

*Carrie Lux*

Lux gives readers an inside look at what life is like with cystic fibrosis.

### **Sticky Icky Booger Bugs**

*Sherry Frith*

Kory is a normal kid who loves to do kid things. He also has cystic fibrosis – but he knows how to take care of himself and have fun every day!

### **Cadberry's Letters**

*Jennifer Racek*

Written for pre-school aged children, Cadberry's Letters introduces children to life with cystic fibrosis.

*Need more information?*

## **Child Health Information Specialist**

 403-955-7745  [ChildHealthInfo@ahs.ca](mailto:ChildHealthInfo@ahs.ca)

 [fcr.cahs.ca/rx/cystic-fibrosis](http://fcr.cahs.ca/rx/cystic-fibrosis)

### **Family & Community Resource Centre**

2<sup>nd</sup> Floor, Alberta Children's Hospital  
28 Oki Drive NW, Calgary, AB, T3B 6A8

This material is designed for information purposes only. It should not be used in place of medical advice, instruction and/or treatment. If you have specific questions, please contact your doctor or appropriate health care professional.



Alberta Health  
Services

Alberta Children's Hospital





# APPENDIX G

The following is a list of contact information, by province, for all the CF clinics across Canada.

## ALBERTA

<b>Alberta Children's Hospital</b> (paediatric) 2888 Shagnappi Trail NW Calgary, Alberta T3B 6A8 <b>Director:</b> Dr. C. Bjornson <b>Nurse Coordinator:</b> Lori Fairservice	<b>Clinic:</b> 403-955-7319 <b>Emergency:</b> 403-955-7211 <b>Office:</b> 403-955-2952 <b>Fax (Office):</b> 403-955-7527
<b>Foothills Hospital</b> (adult) Health Sciences Centre, 3330 Hospital Dr. NW Calgary, Alberta T2N 4N1 <b>Director:</b> Dr. M. Parkins <b>Nurse Coordinator:</b> Linda Fatovich	<b>Clinic:</b> 403-220-5951 <b>Emergency:</b> 403-944-1110 <b>Office:</b> 403-220-5951 <b>Fax (Clinic):</b> 403-270-2772
<b>Stollery Children's Hospital</b> (paediatric) Walter Mackenzie Centre 2E2.24 8440 – 112 Street Edmonton, Alberta T6G 2B7 <b>Director:</b> Dr. T. Kherani <b>Nurse Coordinator:</b> Amanda Jober	<b>Clinic:</b> 780-407-4897 <b>Emergency:</b> 780-407-8822 <b>Fax (Clinic):</b> 780-407-6274 <b>Nursing line:</b> 780-407-8341
<b>University of Alberta Hospitals</b> (adult) 3-111B Clinical Sciences Building 11350 83 Avenue Edmonton, Alberta T6G 2G3 <b>Director:</b> Dr. N. Brown <b>Nurse Coordinator:</b> Crystal Howell	<b>Clinic:</b> 780-407-6745 <b>Emergency:</b> 780-407-8822 <b>Fax (Clinic):</b> 780-407-3112

## BRITISH COLUMBIA

<p><b><u>BC Children’s Hospital</u></b> (paediatric) Room K3-189 Ambulatory Care Building 4480 Oak Street Vancouver, British Columbia V6H 3V4 <b>Director:</b> Dr. M. Chilvers <b>Nurse Coordinator:</b> Anna Gravelle</p>	<p><b>Clinic:</b> 604-875-2345 x 7005 <b>Emergency:</b> 604-875-2134 <b>Main:</b> 888-300-3088 <b>Office:</b> 604-875-2146 <b>Fax:</b> 604-875-2349</p>
<p><b><u>St. Paul’s Hospital</u></b> (adult) 1081 Burrard Street Vancouver, British Columbia V6Z 1Y6 <b>Director:</b> Dr. P. Wilcox <b>Nurse Coordinator:</b> Jane Kerr</p>	<p><b>Clinic Office:</b> 604-806-8522 <b>CF Nurses:</b> 604-682-2344 x63892 <b>Hospital Switchboard:</b> 604-682-2344 <b>CF Clinic Fax:</b> 604-806-8122</p>
<p><b>Victoria General Hospital</b> (paediatric) #1 Hospital Way Victoria, British Columbia V8Z 6R5 <b>Director:</b> Dr. S. Kent <b>Nurse Coordinator:</b> Alison Manning</p> <p><i>(The <b><u>Victoria Adult Clinic site</u></b> includes contact information for the Victoria Pediatric CF Clinic)</i></p>	<p><b>Clinic office:</b> 250-727-4385 <b>CF Nurses:</b> 250-727-4451 or 250-727-4450 <b>Hospital Switchboard:</b> 250-727-4212 <b>CF Clinic Fax:</b> 250-727-4211</p>
<p><b><u>Royal Jubilee Hospital</u></b> (adult) Royal block 4, RB 422 1952 Bay Street Victoria, British Columbia V8R 1J8 <b>Director:</b> Dr. Aaron Young <b>Nurse Coordinator:</b> Grant Hoffert</p>	<p><b>Office:</b> 250 370 8111 local 13395 <b>Fax (Clinic):</b> 250 370 8157</p>

## MANITOBA

### **Children's Hospital of Winnipeg**

(paediatric)

840 Sherbrook Street – Room CS 516

Winnipeg, Manitoba R3A 1S1

**Nurse Coordinators:** Jane Mayo,

Jocelyne Arpin

Medical Director: Dr. Raquel Consunji -Araneta

**Clinic:** 204-787-8834

**After-hours:** 204-787-2071

**Office:** 204-787-4753

**Fax:** 204-787-1944

**Nurse:** 204-787-2079

**Nurse:** 204-787-2485

### **Health Sciences Centre (adult)**

RS105-820 Sherbrook Street

Winnipeg, Manitoba R3A 1R8

**Director:** Dr. Nancy Porhownik

**Nurse Coordinator:** Jody Hainstock

**Clinic:** 204-787-2384

**Main:** 204-787-3661

**Office:** 204-787-2338

**Fax:** 204-787-2420

**Nurse:** 204-787-1521

## NEW BRUNSWICK

### **Horizon Health Network**

(adult/paediatric)

Saint John Regional Hospital

P.O. Box 2100

Saint John, New Brunswick E2L 4L2

**Directors:** Dr. W. Alexander (paediatric)

Drs. G. Bishop and O. Andreani

(adult)

**Nurse Coordinator:** Beth MacCready

**Clinic:** 506-648 6793

**Clinic (Nurse):** 506-648-6057

**Emergency:** 506-648 6000

**Office:** 506-648 6811

**Fax:** 506-648-6790

## NEWFOUNDLAND AND LABRADOR

### **The Janeway Site (paediatric) Health**

**Sciences Centre (adult)**

300 Prince Philip Drive

St. John's, Newfoundland and Labrador

A1B 3V6

**Director:** Gokul Vidyasankar

**Clinic Coordinator:** Karen Doyle

**Clinic:** 709-777-4389

**Main:** 709-777-4222

**Office:** 709-777-4326

**Fax:** 709-738-4151

## NOVA SCOTIA

<p><b>I.W.K. Health Centre</b> (paediatric) 5850/5980 University Avenue P.O. Box 9700 Halifax, Nova Scotia B3K 6R8 <b>Director:</b> Dr. D. Hughes <b>Nurse Coordinator:</b> Paula Barrett</p>	<p><b>Clinic:</b> 902-470-8219 <b>Emergency:</b> 902-470-8050 <b>Office:</b> 902-470-8219 <b>Fax:</b> 902-470-7223</p>
<p><b>QE II Health Sciences Centre</b> (adult) 1796 Summer Street Halifax, Nova Scotia B3H 3A7 <b>Director:</b> Dr. N. Morrison <b>Nurse Coordinator:</b> Fran Gosse</p>	<p><b>Clinic:</b> 902-473-4024 <b>Office:</b> 902-473-4024 <b>Fax (office):</b> 902-425-8962 <b>Fax (clinic):</b> 902-473-6202</p>

## ONTARIO

<p><b>Children's Hospital of Eastern Ontario</b> (paediatric) 401 Smyth Road Ottawa, Ontario K1H 8L1 <b>Directors:</b> Dr. Joe Reisman <b>Nurse Coordinator:</b> Joanne Hammel</p>	<p><b>Clinic:</b> 613-737-7600 x 2214 <b>Emergency:</b> 613-737-7600 <b>Office:</b> 613-737-7600 <b>Fax:</b> 613-738-4298</p>
<p><b>Ottawa General Hospital</b> (adult) 501 Smyth Road Ottawa, Ontario K1H 8L6 <b>Director:</b> Dr. S. Aaron <b>Nurse Coordinator:</b> Ena Gaudet</p>	<p><b>Clinic:</b> 613-737-8899 x 78100 <b>Emergency:</b> 613-737-8146 <b>Office:</b> 613-737-8899 x 74729 <b>Fax:</b> 613-739-6807</p>
<p><b>Hotel Dieu Hospital</b> (adult/paediatric) 166 Brock Street Kingston, Ontario K7L 5G2 <b>Directors:</b> Dr. R. van Wylick (paediatric) Dr. D. Lougheed (adult) <b>Nurse Coordinator:</b> Lisa Smith</p>	<p><b>Clinic:</b> 613-544-3400 x 3147 <b>Main:</b> 613-544-3310 <b>Office (adult):</b> 613-548-2348 <b>Office (paediatric):</b> 613-544-3400 x 3359 <b>Fax (clinic):</b> 613-544-3559</p>

## ONTARIO

<p><b>The Hospital for Sick Children</b> (paediatric) 555 University Avenue Toronto, Ontario M5G 1X8 <b>Director:</b> Dr. M. Solomon <b>Nurse Practitioner:</b> Kate Gent</p>	<p><b>Clinic:</b> 416-813-5826 <b>Main:</b> 416-813-1500 <b>Office:</b> 416-813-6167 <b>Fax (clinic):</b> 416-813-6246</p>
<p><b>St. Michael's Hospital</b> (adult) 30 Bond Street Toronto, Ontario M5B 1W8 <b>Director:</b> Dr. E. Tullis <b>Nurse Coordinator:</b> Sandee Westell</p>	<p><b>Clinic:</b> 416-864-5409 <b>Emergency:</b> 416-864-5431 <b>For Appointment:</b> 416-864-5764 <b>Office:</b> 416-864-5406 <b>Fax (clinic):</b> 416-864-5651</p>
<p><b>Hamilton Health Sciences Corporation</b> (paediatric) <b>McMaster Children's Hospital</b> 1200 Main Street West, 2nd Floor, 2G Hamilton, Ontario L8N 3Z5 <b>Director:</b> Dr. L. Pedder <b>Nurse Coordinator:</b> Val Carroll</p>	<p><b>Appointments:</b> 905-521-2100 x 78515 <b>Fax (clinic):</b> 905-524-5707 <b>Office:</b> 905-521-2100 x 73508 <b>Coordinator:</b> 905-521-2100 x 73086 <b>Emergency:</b> 905-521-2100</p>
<p><b>Hamilton Health Sciences Corporation</b> (adult) <b>McMaster University Medical Centre</b> 1200 Main Street West, Room 3V2 Hamilton, Ontario L8N 3Z5 <b>Director:</b> Dr. A. Freitag <b>Nurse Coordinator:</b> Kelly Campbell</p>	<p><b>Clinic:</b> 905-521-2100 x 75711 <b>Emergency:</b> 905-521-2100 <b>Office:</b> 905-521-2100 x 76216 <b>Fax (clinic):</b> 905-521-5073 <b>Coordinator:</b> 905-521-2100 x 75711</p>
<p><b>London Health Sciences Centre</b> (paediatric) Children's Hospital, VH PMDU Zone E-400 800 Commissioners Road East London, Ontario N6A 5W9 <b>Director:</b> Dr. April Price <b>Nurse Coordinator:</b> Jennifer Itterman</p>	<p><b>Clinic:</b> 519-685-8500 x 52692 <b>Emergency:</b> 519-685-8141 <b>Office:</b> 519-433-2242 x 52032 <b>Fax (clinic):</b> 519-685-8130</p>
<p><b>London Health Sciences Centre</b> (adult) <b>South Street Hospital Clinic</b> 375 South Street London, Ontario N6A 4G5 <b>Director:</b> Dr. James Lewis <b>Adult Nurse Case Manager:</b> Tracy Gooyers</p>	<p><b>Clinic:</b> 519-685-8500 x 55186 <b>Emergency:</b> 519-685-8141 <b>Office:</b> 519-667-6548 <b>Fax (clinic):</b> 519-685-8130</p>

## ONTARIO

<b>Grand River Hospital</b> (paediatric) Kitchener-Waterloo Site 835 King Street West Kitchener, Ontario N2G 1G3 <b>Director:</b> Dr. L. Pineau <b>Nurse Coordinator:</b> Arlene Valenta	<b>Clinic:</b> 519-749-6868 x 1 <b>Main:</b> 519-742-3611 <b>Office:</b> 519-741-8660 <b>Fax (clinic):</b> 519-749-4317
<b>St. Mary's General Hospital</b> (adult) 911 Queen's Boulevard Kitchener, Ontario N2M 1B2 <b>Director:</b> Dr. M. Jackson <b>Nurse Coordinator:</b> Lori Peterson	<b>Clinic:</b> 519-749-4300 x 3716 <b>Main:</b> 519-744-3311 <b>Office:</b> 519-749-6868 #1 <b>Fax (clinic):</b> 519-749-4317
<b>Windsor Regional Hospital</b> (paediatric) 1995 Lens Avenue Windsor, Ontario N8W 1L9 <b>Director:</b> Dr. L. Morgan <b>Clinic Coordinators:</b> Sue Grebe Michelle Murray	<b>Clinic:</b> 519-254-5577 <b>Emergency:</b> 519-254-5577 x 52222 <b>Office:</b> 519-944-9924 <b>Fax (office):</b> 519-944-7282
<b>Sudbury Regional Hospital</b> (adult/paediatric) 41 Ramsey Lake Road Sudbury, Ontario P3E 5J1 <b>Director:</b> Dr. V. Kumar <b>Nurse Coordinator:</b> Sharri-Lynne Zinger	<b>Clinic:</b> 705-522-2200 x 3263 <b>Main:</b> 705-523-7100 <b>Office:</b> 705-674-1499 <b>Fax (clinic):</b> 705-523-7288

## PRINCE EDWARD ISLAND

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:

<b>I.W.K. Health Centre</b> <b>Nurse Coordinator:</b> Paula Barrett	<b>Clinic:</b> 902-470-8219 <b>Office:</b> 902-470-8219 <b>Fax:</b> 902-470-7223
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## QUÉBEC

<p><b>Centre hospitalier régional de Rimouski (CHRR)</b> – (adult/paediatric) 150, avenue Rouleau Rimouski, Québec G5L 5T1 <b>Directors:</b> Dr. Steeve Goulet <b>Nurse Coordinator:</b> Geneviève Gagné</p>	<p><b>Clinic:</b> 418-724-3000 x 8768 <b>Fax:</b> 418-725-3025 <b>Office:</b> 418-724-4221</p>
<p><b>Centre hospitalier de l'Université Laval (CHUL)</b> – paediatric 2705, boul. Laurier Sainte-Foy, Québec G1V 4G2 <b>Directors:</b> Dr. P. Daigneault <b>Nurse Coordinator:</b> Manon Roussin</p>	<p><b>Clinic:</b> 418-656-4141 x 47506 <b>Emergency:</b> 418-656-4141 <b>Fax:</b> 418-654-2137 <b>Office:</b> 418-654-2282</p>
<p><b>Institut Universitaire de Cardiologie et de Pneumologie de Québec (IUCPQ)</b> – (adult) Hôpital Laval 725, chemin Sainte-Foy Québec, Québec G1V 4G5 <b>Director:</b> Dr. L. Bilodeau <b>Nurse Coordinator:</b> Ève Routhier</p>	<p><b>Clinic:</b> 418-656-8711 x 3538 <b>Office:</b> 418-656-8711 <b>Fax:</b> 418-656-4557</p>
<p><b>Centre universitaire de santé de Sherbrooke (CHUS)</b> – (adult/paediatric) 3001, 12e Av. Nord, local 9545 Fleurimonty, Québec J1H 5N4 <b>Directors:</b> Dr. L. Rivard (paediatric) Dr. A. Cantin (adult) <b>Nurse Coordinator:</b> Josée Lessard</p>	<p><b>Clinic:</b> 819-346-1110 x 12820 <b>Fax (Clinic):</b> 819-820-6487 <b>Emergency:</b> 819-346-1110 <b>Office:</b> 819-346-1110 x 12820</p>
<p><b>Centre de santé et de services sociaux de Chicoutimi (CSSSC)</b> - (adult/paediatric) Hôpital de Chicoutimi 305, rue St-Vallier, C.P. 33 Chicoutimi, Québec G7H 5H6 <b>Dectors:</b> Dr. M. Milot (paediatric) Dr. C. Allard (adult) <b>Nurse Coordinator:</b> Maryse Bandet</p>	<p><b>Clinic:</b> 418-541-1037 <b>Emergency:</b> 418-541-1037 <b>Office:</b> 418-549-1034 <b>Fax (Office):</b> 418-541-1134</p>

## QUÉBEC

<p><b>Centre Hospitalier Universitaire (CHU) Mère-Enfant (CHUSJ)</b> – (paediatric) Hôpital Sainte-Justine 3175, chemin de la Côte Ste-Catherine Montréal, Québec H3T 1C5 <b>Director:</b> Dr. J.-É. Marcotte <b>Nurse Coordinators:</b> Isabelle Tellier Manon Caissy</p>	<p><b>Clinic:</b> 514-345-4931 x 6045 <b>Emergency:</b> 514 345-4931 x 4919 <b>Office:</b> 514 345-4724 <b>Fax (office):</b> 514-345-4804</p>
<p><b>Centre hospitalier de l'Université de Montréal (CHUM)</b> – (adult) 1051, rue Sanguinet Montréal, Québec H2X 0C1 <b>Director:</b> Dr. A. Lavoie <b>Nurse Coordinators:</b> Yung-Chun Chou Alicia Brindle-Tessier <b>Social Worker:</b> Marie-Ève Major</p>	<p><b>Clinic:</b> 514-890-8000 x 15667 <b>Emergency:</b> 514-890-8000 x 14444 <b>Fax:</b> 514-412-7002 <b>Extension</b> 14432 <b>Extension</b> 14802 <b>Extension</b> 14253</p>
<p><b>Centre universitaire de santé McGill (CUSM)</b> – (adult) Institut Thoracique de Montréal 1001, boul. Décarie Montréal, Québec H4A 3J1 <b>Director:</b> Dr. E. Matouk <b>Nurse Coordinator:</b> Jade Ostiguy-Robillard</p>	<p><b>Clinic:</b> 514-934-1934 x 32121 <b>Emergency:</b> 514-934-1934 x 32567 <b>Office:</b> 514-934-1934 x 32559 <b>Fax (clinic):</b> 514-843-2070</p>
<p><b>Centre universitaire de santé McGill (CUSM) Hôpital de Montréal pour Enfants (HME)</b> (paediatric) 1001, boul. Décarie Montréal, Québec H4A 3J1 <b>Director:</b> Dr. L. Lands <b>Nurse Coordinators:</b> Deborah Fertuck</p>	<p><b>Clinic:</b> 514-412-4400 x 22643 <b>Emergency:</b> 514-412-4400 <b>Office:</b> 514-412-4444 <b>Fax:</b> 514-412-4364</p>
<p><b>Centre de santé et services sociaux de Rouyn-Noranda (CSSRN)</b> – (adult/paediatric) 4, 9e Rue Rouyn-Noranda, Québec J9X 2B2 <b>Directors:</b> Dr. C. Popa (paed.) Dr. L. Perreault (adult) <b>Nurse Coordinator:</b> Claire Myre</p>	<p><b>Clinic:</b> 819-762-0995 <b>Emergency:</b> 819-764-5131 <b>Office:</b> 819-762-0995 <b>Fax:</b> 819-797-6837</p>



## SASKATCHEWAN

<p><b>Regina General Hospital</b> (paediatric) 1440-14th Avenue Regina, SK S4P 0W5 <b>Director:</b> Dr. B. Holmes <b>Nurse Coordinator:</b> Tess Trenker</p>	<p><b>Clinic:</b> 306-766-4289 <b>Emergency:</b> 306-766-4213 <b>Main:</b> 306-766-4444 <b>Office:</b> 306-352-4900 <b>Fax:</b> 306-766-4946</p>
<p><b>Royal University Hospital</b> (paediatric) 103 Hospital Drive Saskatoon, SK S7N 0W8 <b>Director:</b> Dr. Martha McKinney <b>Nurse Coordinator:</b> Lorna Kosteniuk</p>	<p><b>Clinic:</b> 306-655-2948 <b>Afterhours:</b> 306-655-1000 <b>Office:</b> 306-844-1275 <b>Fax:</b> 306-844-1514</p>
<p><b>Royal University Hospital</b> (adult) 103 Hospital Drive Saskatoon, SK S7N 0W8 <b>Director:</b> Dr. J. Tam <b>Nurse Coordinator:</b> Niki Afseth</p>	<p><b>Clinic:</b> 306-655-6781 <b>Afterhours:</b> 306-655-1000 <b>Office:</b> 306-844-1135 <b>Fax:</b> 306-844-1532 <b>Email:</b> <a href="mailto:adultCFclinic@saskhealthauthority.ca">adultCFclinic@saskhealthauthority.ca</a></p>

<sup>i</sup> Cystic Fibrosis Canada's 2017 Canadian Cystic Fibrosis Registry, p. 4