



2022 Canadian resource guides for individuals and families affected by primary immunodeficiency

Wendy Shama^{a,b,c*}

ABSTRACT

A diagnosis of immunodeficiency can be challenging for families as they navigate the emotional impact of this diagnosis, as well the potential financial burden of treatment. As is the case with many rare diseases, there existed a paucity of information for families looking for appropriate resources related to their diagnosis. The Primary Immunodeficiency Social Work Network was established in 2011 by Immunodeficiency Canada to develop a network of social workers across Canada who work with patients diagnosed with primary immunodeficiency. This network has had a focus on support programs, education, and research. Resource guides were created by the network with the goal of providing comprehensive support and information on resources available for families and individuals affected by primary immunodeficiency in each province as well as those available nationally.

Statement of Novelty: National and provincial resources guides, reviewed and updated yearly, have been created for families and individuals affected by primary immunodeficiency.

Background

A diagnosis of immunodeficiency can be challenging for families as they navigate the emotional impact of this diagnosis, as well as the potential financial burden of treatment. For rare diseases such as primary immunodeficiency (PI), patients are often required to take a proactive role in managing their own care and may be engaged with healthcare providers who have minimal experience with PI disease. These providers may also have limited access to information on the resources available for this population. A review of the information available showed that a paucity of information existed for these families who were looking for appropriate resources related to their diagnosis. The PI Social Work Network was established in 2011 by Immunodeficiency Canada to develop a network of social workers across Canada who work with patients diagnosed with PI. This network has

had a focus on support programs, education, and research. Resource guides were created by the network to support families by providing information on both provincial as well as national resources available. While these lists are not exhaustive, there is an attempt to keep them as up to date as possible. The current guide was updated in February 2022. If additional psychosocial support would be beneficial or a family requires support accessing resources, they should be directed to their local hospital social worker, or they may contact Wendy Shama, MSW, RSW, at Immunodeficiency Canada.

National resources

Financial resources

Canada Child Benefit (CCB)

This is a tax-free monthly payment made to eligible families to help them with the cost of raising children

^aHospital for Sick Children, Department of Social Work; ^bFactor-Inwentash Faculty of Social Work, University of Toronto, Toronto, ON; ^cImmunodeficiency Canada, Toronto, ON

*Corresponding author: Wendy Shama/Wendy.shama@sickkids.ca/wendy.shama@immunodeficiency.ca

Submitted 25 February 2022

Accepted 27 February 2022

Available online 27 February 2022

LymphoSign Journal 9:17–31 (2022)
dx.doi.org/10.14785/lymphosign-2022-0003

under 18 years of age. The CCB might include the child disability benefit and any related provincial and territorial programs. The Canada Revenue Agency uses information from your income tax and benefit return to calculate how much your CCB payments will be. To get the CCB, you have to file your return every year, even if you did not have income in the year. If you have a spouse or common-law partner, they also have to file a return every year.

<https://www.canada.ca/en/revenue-agency/services/child-family-benefits/canada-child-benefit-overview.html>

Child Disability Benefit

If approved for the Disability Tax Credit, you are automatically assessed for this benefit. You do not need to apply. This benefit is based on family income, is tax-free, and paid monthly for low to moderate income families caring for a child under the age of 18 with a severe and prolonged impairment in mental or physical functions.

<https://www.canada.ca/en/revenue-agency/services/child-family-benefits/child-disability-benefit.html>

Disability Tax Credit

The Disability Tax Credit (DTC) is known as the “disability amount” on your income tax return. The DTC is a non-refundable credit that reduces the amount of income tax that a person with a disability, or their supporting person, might otherwise have to pay. The DTC is also used to determine eligibility for the Child Disability Benefit, an amount available under the Canada Child Tax Benefit for a child under 18 with a disability. In order to claim the DTC, a person must file a completed Form T2201, Disability Tax Credit Certificate, signed by a qualified person. Forms are available at CRA offices, or by calling 1-800-959-2221; the form can also be downloaded from the CRA Website.

<https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html>

EI Caregiving Benefits & Leave

Through Employment Insurance, you could receive financial assistance of up to 55% of your earnings, to a maximum of \$562 a week to provide care or support to a critically ill or injured person or someone needing end-of-life care. As a caregiver, you don't have to be

related to or live with the person you care for or support, but they must consider you to be like family.

There are two different types of Benefits:

- Family Caregiver Benefits for Children
Time off is needed to care for an ill child. Maximum weeks payable up to 35 weeks.
- Compassionate Care Benefits
End-of-life care is defined as providing care or support to a person who has a serious medical condition with a significant risk of death within 26 weeks. Maximum weeks payable up to 26 weeks.

Prerequisites:

- Your regular weekly earnings from work have decreased by more than 40% for at least one week because you need to take time away from work to provide care or support to the person. You accumulated 600 insured hours of work in the 52 weeks before the start of your claim, or since the start of your last claim, whichever is shorter.
- Medical Certificate from Physician is needed.

<https://www.canada.ca/en/services/benefits/ei/caregiving.html>

Canada Caregiver Credit

This is a tax credit that can be applied for when filing your current year tax return. The child must have a medical or physical infirmity and as a result of that infirmity is, and is likely to be for a long continued period of indefinite duration, dependent on others for significantly more assistance in attending to the child's personal needs and care when compared to children of the same age.

<https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/canada-caregiver-amount.html>

Medical Expenses Tax Credit

This applies to individuals who have significant medical expenses for themselves or their dependents. This is an income tax credit which is claimed when filing your current year tax return.

<https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/lines-33099-33199-eligible-medical-expenses-you-claim-on-your-tax-return.html>

Programs and services

Big Brothers and Big Sisters of Canada

Each Big Brother/Big Sister agency provides direct service to children by matching adults and children in quality mentoring relationships. Agency staff members are experts at screening volunteers and matching them with a child having similar interests.

www.bigbrothersbigsisters.ca

Easter Seals Canada

Since 1922, Easter Seals has been leading the way to opportunities for Canadians with disabilities. Easter Seals operates as a network of provincially licensed members that deliver programs and services to Canadians with physical disabilities in their community.

<https://easterseals.ca/english/>

Immune Deficiency Foundation

This is a national non-profit health organization dedicated to improving the diagnosis and treatment of primary immune deficiency diseases through research and education. IDF is governed by a Board of Trustees, has an active Medical Advisory Committee comprised of prominent clinical immunologists, a nationwide volunteer support network, and a dedicated professional staff.

<https://primaryimmune.org/>

Jordan's Principle

Jordan's Principle helps First Nations children living in Canada to access products, services, and supports that they need. Funding can help with a wide range of health, social, and educational needs.

<https://www.sac-isc.gc.ca/eng/1568396042341/1568396159824#chp02>

Make-A-Wish Canada

Children's Wish/Make A Wish have merged as Make-A-Wish Canada. Their mission is to grant the wishes of children with life-threatening medical conditions. Their goal is to ensure that all experiences create lifelong memories for the wish child and believe that each wish experience should be as unique and special as the child who wished for it.

Children may only have ONE wish either through Make-A-Wish or Starlight Foundation.

<https://makeawish.ca/>

MedicAlert Foundation of Canada

Canada MedicAlert Foundation offers free medic alert bracelets to children across Canada. *No Child Without* includes a free medical identification bracelet and electronic health record with 24/7 access so that critical health information is quickly available during a medical emergency. MedicAlert memberships are for students (from age 4 to their 14th birthday) in select schools (www.nochildwithout.ca). The *Membership Assistance Program* ensures that any person with potentially life-threatening medical conditions can have access to services offered by MedicAlert, regardless of his/her ability to pay.

<http://www.medicalert.ca/education/en/programs/assistance.asp>

National Organization for Rare Disorders

This is a federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

www.rarediseases.org

Primary Immunodeficiency Resource Center

This website is designed to be a central resource on Primary Immunodeficiency. Its goal is to allow researchers, scientists, physicians, government, industry, patients and their families to be able to access this information quickly, efficiently, and seamlessly.

<http://www.info4pi.org/>

Shine Through the Rain Foundation

This foundation helps families who have a child with a life-threatening illness.

The Rainy Day Fund provides emergency payments directly to the utility companies and landlords, as well as grocery gift cards & hospital transportation and parking costs. Shine Through The Rain also reviews special requests for consideration above and beyond the scope of services already covered.

<https://shinethroughtherain.ca/>

Songs of Love

Songs of Love is a non-profit organization that provides personalized songs for children and young adults with a life-threatening or chronic illness.

www.songsoflove.org

Starlight Children's Foundation Canada

Starlight Children's Foundation is a non-profit organization dedicated to making a world of difference for seriously ill children and their families. Starlight offers an array of in-hospital, out-patient, school, and home-based programs and services that help to brighten the lives of children and families facing serious illnesses. *Child may only have ONE wish either through Make-A-Wish, or Starlight Foundation.*

www.starlightcanada.org

Transportation

Air Canada Kids Horizon Program

This program provides free flights for children and a caregiver traveling anywhere in Canada for clinic appointments. Please contact your local children's hospital for availability. Families are responsible for taxes and fees.

<http://www.aircanada.com/en/about/community/kids.html>

Hope Air

Hope Air (formerly Mission Air) is a national Canadian charity that arranges free air transportation for Canadians that need to travel to non-emergency medical care outside of their home communities and cannot afford the flight costs. To make a flight request or for more information call the bilingual staff Monday through Friday, 9:00 AM – 4:30 PM EST or visit them at their website.

<https://hopeair.ca/>

Wigs

A Child's Voice–Angel Hair for Kids

Angel Hair for Kids provides wigs for eligible children who have hair loss due to chemotherapy, radiation, burns, or alopecia. This is a program through A Child's Voice Foundation.

<https://www.acvf.ca/angel-hair-for-kids>

Wigs for Kids

This is a non-profit organization that provides hair replacement systems for eligible children 18 years or younger who have hair loss as a result of chemotherapy, alopecia, radiation treatments, burns, or other medical circumstances.

www.wigsforkids.org

Immunodeficiency Canada

Emergency financial assistance

The Alastair Fund provides funding to families dealing with financial strain due to illness from a primary immunodeficiency. It is available to families with a child registered as a patient at: Alberta's Children's Hospital, British Columbia's Children's Hospital, Montreal's Children's Hospital, and Toronto Hospital for Sick Children. Families can access financial assistance for transportation, overnight stays, food, parking, and other critical needs. Families should talk to the Hospital Social Work Department to access this fund.

Publications

Immunodeficiency Canada strives to provide information that is relevant and up to date. Some materials are available in both English and French. Many materials are downloadable or print copies may be requested. Resources Guide for individuals and families affected by Primary Immunodeficiency include:

- What is Primary Immunodeficiency pamphlet
- 10 Warning Signs
- Newsletters (current and past issues)

www.immunodeficiency.ca

Social media

Individuals are invited to join others affected by Primary Immunodeficiency and stay up to date through social media. Look for Immunodeficiency Canada on Facebook, LinkedIn, and the YouTube Channel.

Social events

Immunodeficiency Canada sponsors and hosts events for families, adults, teens, and children to help break the isolation many individuals and families feel and build networks of mutual support. Kids' picnics have been held in Montreal, Toronto, and Calgary organized in partnership through local health care facilities. In the Greater Toronto Area, meet and greet evenings for

adults and fun-filled events for teens are organized each year.

Provincial resources—Alberta

Accommodation

Ronald McDonald House of Southern Alberta

111 West Campus Place NW
Calgary, Alberta T3B 2R6
Tel: 403-240-3000

<https://rmhcalberta.org/>

Dental

Recipients of Income Supports, Alberta Child Health Benefit or the Alberta Adult Health Benefit may receive coverage for extraordinary dental work. Their dentist needs to provide information to the applicable program which will then send a claim through the ADSC via a Health Benefits Exception request.

Financial resources

Alberta Aids to Daily Living Program (A.A.D.L.)

This provides funding for some medical supplies and equipment and is available to all residents of Alberta. The cost share is A.A.D.L. 75% and the family 25%.

Edmonton: 780-427-0731, or toll free in Alberta: 310-0000, then 780-427-0731.

<https://www.alberta.ca/aadl-eligibility-and-application-for-benefits.aspx>

Alberta Adult Health Benefit/ Alberta Child Health Benefit programs

Alberta Adult Health Benefit/ Alberta Child Health Benefit programs are designed to assist families meet daily needs. Qualifying families may receive support for items such as prescription drugs, eye glasses, and diabetic supplies.

Edmonton 780-427-6848 or 1-877-469-5437 (toll free province wide).

<http://humanservices.alberta.ca/financial-support/2076.html>

Alberta Works Housing and Utility support

Alberta Works Housing and Utility support offers Albertans access to emergency accommodation, transportation, and meals when criteria are met.

Edmonton 780-644-5135 (24 hour/day, 7 days/week).
Across Alberta 1-866-644-5135

www.humanservices.alberta.ca/financial-support/3171.html

Community Key

Community Key helps families with children that are seriously-ill or critically-injured that spend a lot of time in hospital. They help with up to 2 months of mortgage support (or up to \$2000).

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

Eye See... Eye Learn Program

This program was initiated by the Alberta Association of Optometrists. Children in Kindergarten are eligible to receive free glasses and frames.

Tel: 1-855-424-ESEL (3735)

www.eyeseeeyearn.ca

Family Support for Children with Disabilities (FSCD)

The FSCD program uses a family-centered approach to provide parents with funding to access a range of supports and services that strengthen their ability to promote their child's healthy growth and development. In addition, FSCD assists with some of the extraordinary costs of raising a child with a disability. Services are available to eligible children with disabilities and their families until the child turns 18 years old.

<https://www.alberta.ca/fscd.aspx>

Hope for Kids (Mountain View country)

Hope 4 MVC Kids is a charity that provides families with children with a medical diagnosis who live in Mountain View County assistance with expenses including meals, transportation, medical equipment, accommodation, and various bills.

<https://hope4mvckids.org/>

Request for a Health Benefit Exception

Parents/guardians, who receive the Alberta Adult or Child Health Benefit and have a child that has been prescribed a medication that is not listed on the Health and Wellness Drug Benefit List, should refer to instructions pertaining to submitting a "Request for Drugs and Nutritional Products" form. Parents/guardians and the prescribing physician are required to complete forms

that are sent for review by the Health Benefit Review Committee. Requests for Prescribed infant formula and special diet items may also be considered for funding using these forms.

Programs and services

Calgary Immigrant Aid Society

The Calgary Immigrant Aid Society was established in 1977 and has, over the past 30 years, helped over 250 000 immigrants settle into their new life and home in Calgary, Alberta. The organization's focus is on individuals and families first, providing a sense of community and connection.

9107 Ave SW
Calgary, Alberta T2P 3N8
Tel: 403-265-1120

www.immigrantservicescalgary.ca

Children's Link Society

Children's Link Society is a family-centered, community-based, central access point of information for families of children with special needs in Calgary and Area. The Children's Link Society provides drop-in and phone support in walking through steps of transition.

Suite 245, 720 - 28th Street N.E
Calgary, Alberta T2A 6R3
Tel: 403-230-9158

www.childrenslink.ca

Jamie's Preschool

Jamie's Preschool provides a safer haven for immune-compromised children and their siblings. The program aims at keeping children who are immune-compromised, healthy, active, and engaged.

Unit 1, 3303 Capitol Hill Cres. NW
Calgary, Alberta T2M 2R2
Tel: 403-808-2296

www.jamiespreschool.ca

Pace Kids

Pace Kids is a family-focused program and strives to offer excellence in the treatment of children with special needs, emphasizing an intra-disciplinary direct treatment approach. This program is funded by Family Support for Children with Disability (FSCD).

#112 5211 MacLeod Trail S
Calgary, Alberta T2H 0J3
Tel: 403-234-7876

www.pacekids.ca

Provincial resources—British Columbia

Accommodation

Ronald McDonald House British Columbia

4567 Heather St
Vancouver, British Columbia V5Z 0C9
Tel: 604-736-2957
Fax: 604-736-5974

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

Easter Seals House

Easter Seals House in Vancouver provides a low-cost place to stay for more than 100 parents and children every night. For more information:

3981 Oak St
Vancouver, British Columbia V6H 4H5
Tel: 604-736-3475
Reservations only: 1-800-818-3666

<https://www.eastersealsbcy.ca/how-we-help/easter-seals-house/>

Financial resources

BC Family Residence Program

This is a program through The Ministry of Health providing accommodation assistance to enable families to stay together when their child requires medical care at BC Children's Hospital or Sunny Hill Health Centre for Children. Enhanced travel assistance is also provided through improved ground transportation for children and air transportation for patients of all ages.

<http://www.bcfamilyresidence.gov.bc.ca/>

BC PharmaCare

BC PharmaCare helps B.C. residents with the cost of eligible prescription drugs and certain medical supplies. It provides access to drug therapy through several drug plans. The largest is the income based Fair PharmaCare plan which is passed on your family's net income. It is available to single people or to families.

Your coverage is updated on January 1 of every year based on your current income information.

<https://www2.gov.bc.ca/gov/content/health/health-drug-coverage/pharmacare-for-bc-residents>

Friends of Children

Friends of Children is a registered charity providing free and confidential service to Northern BC and East Kootenay families travelling to access medical treatments for their children. Their goal is to relieve emotional and financial strain by assisting with the fuel, accommodation, and meal costs associated with these appointments, surgeries, and consultations. They may also be able to assist with therapies and specialized equipment related to a child's medical condition.

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

Variety, Children's Charity

This provides grants for equipment, medical/therapeutic supplies, specialized therapy, dental/orthodontic treatment, and bursaries for tuition/tutoring/summer camp. They also provide emergency grants to assist with funding to access medical care, supplies, accommodation, transportation, prescriptions, ambulance bills, formula, and breast pumps. The child must be under 19 years, be a BC resident for a minimum of 3 months, have a qualified special need (medical, physical, developmental, cognitive, social, psychiatric, emotional), and be in financial need.

www.variety.bc.ca

Provincial resources—Manitoba

Accommodation

Ronald McDonald House Manitoba

566 Bannatyne Avenue
Winnipeg, Manitoba R3A 0G7
Tel: 204-774-4777

<http://www.rmh.mb.ca>

Will's Place

Will's Place are maintained 2 bedroom fully furnished apartments for families with children undergoing Bone Marrow Transplant (BMT). Referral needed by the BMT team.

Financial resources

Children's Hospital Research Foundation

Children's Hospital Research Foundation is a registered charity that helps with the purchase of equipment, support programs and fund medical research.

<http://goodbear.mb.ca>

Daniel Lee Dorward Compassionate Fund for SickKids

This is a charity of last resort, designed to help families cope with the day-to-day and extraordinary costs of having a child who has a chronic and/or life-threatening illness. Social Workers at Winnipeg Children's Hospital refer families after all other resources have been exhausted. Assistance from this fund reduces some of the financial stress associated with having a seriously ill child.

https://secure.goodbear.ca/site/TR/Events/ThirdParty-Fundraisers?px=1048242&pg=personal&fr_id=1100#.XgOP_fxybb0

Employment and Income Assistance

Employment and Income Assistance (EIA) provides financial help to Manitobans who have no other way to support themselves or their families. For people who are able to work, EIA will help them go back to work by providing supports to employment.

<https://www.gov.mb.ca/fs/eia/index.html>

Lions Foundation of Manitoba and North Western Ontario

Lions Foundation of Manitoba and North Western Ontario supports, promotes and fosters programs for the benefit of both children and adults that are in need of assistance that live in the communities throughout Manitoba and Northwestern Ontario. They assist with three areas: (1) non-medical costs as set forth by Foundation guidelines which would include modest accommodations, meal allowance, and necessary ground transportation and for medication cost over and above those not covered by the present health care system; (2) non-medical costs for treatment not available in the province; and (3) costs to purchase specialized equipment for the physically challenged.

<http://lionsfoundation.org/>

Pharmacare

Pharmacare is a drug benefit program for eligible Manitobans, regardless of disease or 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. The total family income is adjusted to include a spouse and the number of dependents, if applicable. Each year you are required to pay a portion of the cost of your eligible prescription drugs. This amount is your annual Pharmacare deductible. Pharmacare sets your deductible based on your adjusted family income.

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

Variety Manitoba

Variety Manitoba provides special needs program funding for children from newborn to their 18th birthday who are residents of Manitoba. The Special Need qualifies in the category of medical, physical, developmental, cognitive, social, and emotional as recognized by a designated professional and/or where the family is unable to financially afford the item, service, or therapy required.

<http://varietymanitoba.com/>

Westman Dreams for Kids

Westman Dreams for Kids is a non-profit, local registered organization dedicated to helping kids in the Westman area who are affected by a serious illness.

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

Provincial resources—New Brunswick

Financial resources

East Coast Fund

East Coast Fund is accessed by a social worker at SickKids Hospital for families from the East Coast undergoing bone marrow transplant in Toronto. It can assist with expenses related to travel and stay in Toronto. Connect with a SickKids social worker for application to this fund.

Family Supports for Children with Disabilities

Family Supports for Children with Disabilities provides social work support and financial resources to families to assist with the care and support required to

meet the special developmental needs of their child with disability.

http://www2.gnb.ca/content/gnb/en/services/services_renderer.10195.Family_Supports_for_Children_with_Disabilities_.html

Fuel the Care

Fuel the Care provides fuel gift cards to parents who must frequently travel to provide their children with urgent medical care. This program is for families in Atlantic Canada and New England.

<https://www.irvingoil.com/en-CA/discover-irving/fuel-the-care>

The New Brunswick Drug Plan

The New Brunswick Drug Plan is a prescription drug plan that provides drug coverage for uninsured New Brunswick residents who have an active Medicare card. Any New Brunswick resident who has questions about the New Brunswick Drug Plan may call the information line toll free at 1-855-540-7325, email info@nbdrugs-medicamentsnb.ca, and may view the list of eligible drugs covered by the New Brunswick Drug Plan by visiting the New Brunswick Drug Plans Formulary.

<https://www2.gnb.ca/content/gnb/en/departments/health/MedicarePrescriptionDrugPlan/NBDrugPlan.html>

The New Brunswick Prescription Drug Program

The New Brunswick Prescription Drug Program (NBPDP) provides prescription drug benefits to eligible residents of New Brunswick. Information on the eligible beneficiary groups is outlined at <https://www2.gnb.ca/content/gnb/en/departments/health/MedicarePrescriptionDrugPlan/TheNewBrunswickPrescriptionDrugProgram/BeneficiaryGroups.html>

<https://www2.gnb.ca/content/gnb/en/departments/health/MedicarePrescriptionDrugPlan/TheNewBrunswickPrescriptionDrugProgram.html>

Moncton Lion's Sick Kids Fund

Moncton Lion's Sick Kids Fund can provide assistance with travel (for medically referred travel out of town), prescription drug assistance, medical equipment and other support. Children qualify for assistance up until their 19th birthday.

<https://lionssickkids.ca/>

Provincial resources— Newfoundland and Labrador

Accommodation

Ronald McDonald House Newfoundland & Labrador

P.O. Box 28091

St. John's, Newfoundland A1B 1X0

Tel: 709-738-0000

www.OurHouseNL.ca

Financial resources

East Coast Fund

East Coast Fund is accessed by a social worker at SickKids Hospital for families from the East Coast undergoing bone marrow transplant in Toronto. It can assist with expenses related to travel and stay in Toronto. Connect with a SickKids social worker for application to this fund.

Fuel the Care

Fuel the Care provides a fuel gift cards to parents who must frequently travel to provide their children with urgent medical care. This program is for families in Atlantic Canada and New England.

<https://www.irvingoil.com/en-CA/discover-irving/fuel-the-care>

Newfoundland and Labrador Prescription Drug Program

Newfoundland and Labrador Prescription Drug Program provides assistance in the purchase of pharmaceuticals, and some related medical supplies to residents who qualify for benefit coverage. The focus of the program is that residents of the province should not be denied access to health care because of financial need.

<https://www.gov.nl.ca/hcs/prescription/>

Special Assistance Program

Special Assistance Program — Medical equipment and supplies provides basic medical supplies and equipment to assist with activities of daily living for individuals living in the community who meet the eligibility criteria for the program. Benefits of the program include: medical supplies (such as dressings, catheters and incontinent supplies), oxygen and related equipment and supplies, Orthotics such as braces and burn garments, and Equipment such as wheelchairs, commodes, or walkers.

<https://www.gov.nl.ca/hcs/personsdisabilities/fundingprograms-hcs/#scwap>

Special Child Welfare Allowance Program

Special Child Welfare Allowance Program provides assistance with the cost of services/supports to families with a child (under the age of eighteen years) who has a physical or intellectual disability living at home. The assistance is designed to enable families to purchase items and/or services which are necessary due to the child's disability. The amount of monthly assistance for each family is determined through financial need.

<https://www.gov.nl.ca/hcs/personsdisabilities/fundingprograms-hcs/#scwap>

Transportation

The Medical Transportation Assistance Program (MTAP)

The Medical Transportation Assistance Program provides financial assistance to beneficiaries of the Medical Care Plan (MCP) 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 busing services, and taxis when used in conjunction with commercial air travel.

<https://www.gov.nl.ca/hcs/mcp/travelassistance/>

Provincial resources—Nova Scotia

Accommodation

Ronald McDonald House Atlantic Canada

1133 Tower Road

Halifax, Nova Scotia B3H 2Y7

Tel: 902-429-4044

www.rmhatlantic.ca

Halifax Haven

A non-profit organization through the Mennonite Church that provides accommodation for patients while they undergo treatment in Halifax. Shared guest home. Donation of \$40 per day, if possible. A continental breakfast is provided on-site. Military Families may be

able to access emergency accommodation support through the Military Family Resource Centre.

5897 Inglis Street
Halifax, Nova Scotia B3H 1K7 Canada
Tel: 902-421-1650

Financial resources

Fuel the Care

Fuel the Care provides a fuel gift card to assist with a portion of fuel cost to eligible family members who must frequently travel more than 100 km from home to provide their child with urgent medical care and who are not receiving other funding for transportation. This program is for families in Atlantic Canada. It can be accessed through the IWK Health Centre Social Work Department; however, it is subject to availability.

<https://www.irvingoil.com/en-CA/discover-irving/fuel-the-care>

Local Service Clubs

Local Service Clubs also provide support including local chapters of Lion's, Elk's and Kinsmen Clubs. Contact your local service club through websites, telephone book, or personal contacts.

Out-of-Province Travel & Accommodation Assistance

Out-of-Province Travel & Accommodation Assistance provides funds to individuals who are approved to travel out of province for insured medical care that is not available in Nova Scotia. The policy provides a maximum of \$1,000 in travel assistance (round trip) and \$125 per night up to \$1,500 per month in accommodation assistance. This provides assistance for short-term stays. If a longer term stay is anticipated, patients are encouraged to seek longer term accommodations, such as apartment rental.

<https://novascotia.ca/dhw/Travel-and-Accommodation-Assistance/>

Pharmacare options for Nova Scotia

Income Assistance

For families that collect income assistance (IA), the cost of approved medications is a \$5 'co-pay'. If there are more than 3 medications per child, the co-pay can be waived by IA. Over-the-counter medications (like Tylenol or Advil) may be covered with a letter from your doctor (submitted to Income Assistance) stating

the reason this medication is needed, dosage required, how long it is needed, and the monthly cost.

Family Pharmacare

All Nova Scotia families are eligible for this program as well as single adults over age 18. The Nova Scotia Family Pharmacare Program is a provincial drug insurance plan designed to help Nova Scotians with the cost of their prescription drugs. The Program offers protection against drug costs for families who have no drug coverage or if the cost of the prescription drugs becomes a financial burden to them.

This coverage can be paired with private health insurance (e.g., Blue Cross, Great West Life) when co-payment amounts are high or when pre-existing conditions aren't covered.

Low income Pharmacare for children and youth

Children under 18 whose parents collect the NS portion of the Child Tax Benefit (usually requires income less than \$25,000 year) are eligible for this program.

All approved medications cost \$5. For more information, call 1-866-424-1269

Direct family support for children

This program is for children with severe intellectual or physical disabilities.

All medications and over-the-counter drugs can be covered for children in the program with a letter from your doctor.

Condition-specific & palliative care/end of life coverage

Certain health conditions have specific coverage available to families. Coverage may be available for palliative care and end-of-life symptom management or for patients with unique health conditions.

<http://novascotia.ca/dhw/pharmacare/>

Provincial resources—Ontario

Accommodation

Ronald McDonald House Toronto

240 McCaul St.
Toronto, Ontario M5T 1L1
Tel: 416-977-0458

www.rmhtoronto.org

Dental services

Children in Need of Dental Program (CINOT)

CINOT is a program through the Ontario Ministry of Health and Long-Term Care and provides dental coverage for children from birth to Grade 8 or their 14th birthday.

For more information call the INFO line:

Tel: 1-866-532-3161

TTY: 1-800-387-5559

Hours of Operation: 8:30 AM – 5:00 PM

<https://www.toronto.ca/311/knowledgebase/kb/docs/articles/public-health/dental-and-oral-health-services/dental-and-oral-health-services/children-in-need-of-dental-treatment-cinot.html>

Healthy Smiles Ontario

This is a government-funded dental program that provides free preventive, routine, and emergency dental services for children and youth 17 years old and under from low-income households.

The program includes regular visits to a licensed dental provider and covers the costs of treatment including:

- check-ups
- cleaning
- fillings (for a cavity)
- X-rays
- scaling
- tooth extraction
- urgent or emergency dental care (including treatment of a child's toothache or tooth pain)

Children are automatically eligible for Healthy Smiles Ontario if they or their family receive:

- Ontario Works
- Temporary Care Assistance
- Ontario Disability Support Program
- Assistance for Children with Severe Disabilities

Children are eligible for the program if they:

- Are 17 years of age and under live in Ontario are from low-income families

<https://www.ontario.ca/page/services-covered-by-healthy-smiles-ontario>

Financial resources

Assistance for Children with Severe Disabilities (ACSD)

The ACSD program provides financial assistance to parents to help with the extraordinary cost related to their child's severe disability. This program is for low to moderate income families. A qualifying family will receive no less than \$25 per month to no more than \$500 per month to assist with expenses related to illness. In addition, the child will receive drug and dental coverage.

Ministry of Children and Youth Services Client Services Unit

900 Bay Street, M1-57 Macdonald Block, Toronto, Ontario M7A 1R3

Toll Free: 1-866-821-7770

TTY: 1-800-387-5559

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

Assistive Devices Program (ADP)

This program provides funding assistance towards equipment and supplies for people with long-term physical disabilities who need personalized assistive devices. The majority of receipts will receive 75% coverage, and those on Ontario Works or receiving Assistance for Children with Severe Disabilities receive 100% coverage. Examples are medical supplies, mobility devices, prosthetics, orthotics, sensory devices, and diabetes supplies.

<http://www.health.gov.on.ca/en/public/programs/adp/default.aspx>

Jennifer Ashleigh Foundation

The Jennifer Ashleigh Foundation assists children who are seriously ill, are 21 years of age or under, and whose permanent residence is in Ontario. Family income impacts on assistance decisions. The Foundation will consider requests for assistance in the following areas as they are related to the child's illness:

- Emergency financial relief
- Respite for a pre-determined period of time
- Developmental therapies (excluding Hyperbaric Oxygen Treatment) Educational programs, materials, instruction

- Specially adapted computer equipment and software
- Medical treatments not covered by government health plans or insurance Recreation that promotes a child's involvement in the community.

10800 Concession 5
Uxbridge, Ontario L9P 1R1
Tel: 905-852-1799

Easter Seals Incontinence Supplies Grant

The program is for children and youth between the ages of 3 to 18 years of age with a chronic disability resulting in irreversible incontinence lasting longer than 6 months. Some children under the age of 3 may be eligible for funding depending on their diagnosis. The application must be completed and signed by a medical physician licensed to practice in Ontario. The child must be a resident of Ontario and hold a valid Ontario health card.

For more information on the incontinence supplies grant contact:

Julianna Phen
Easter Seals Ontario
One Concorde Gate, Suite 700
Toronto, Ontario M3C 3N6
Tel: 1-800-668-6252 ext. 314

<https://services.easterseals.org/incontinence-supplies-grant/>

Special Services at Home (SSAH)

This program helps families who are caring for a child with a developmental or physical disability, as well as adults with a developmental disability. It helps families pay for special services in the home or outside the family home as long as the child is not receiving support from a residential program.

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

Ministry of Children and Youth Services Client Services Unit

900 Bay Street, M1-57 Macdonald Block
Toronto, Ontario M7A 1R3
Toll Free: 1-866-821-7770
TTY: 1-800-387-5559

www.gov.on.ca/mcys

Trillium drug program (TDP)

The Trillium Drug Program (TDP) is for people who spend approximately 3 to 4 per cent or more of their after-tax household income on prescription-drug costs. The incomes of TDP household members under age 25 would still be factored into the household deductible calculation. However, any medications funded through OHIP+ (for children and youth that do not have coverage through a private plan) do not contribute towards the household's TDP deductible, as they are not considered out-of-pocket expenses.

For more information:

P.O. Box 337, Station D
Etobicoke, Ontario M9A 4X3
Tel: 416-642-3038
Fax: 416-642-3034
Toll-Free: 1-800-575-5386
Email: trillium@resolve.com

<https://www.ontario.ca/page/get-help-high-prescription-drug-costs>.

Programs and services

Child Development Institute

Child Development Institute offers a wide range of programs and services for children aged 0-12 and their families. In some programs they are able to remain connected with children up to age 18. In all programs the commitment is to strengthen families and promote healthy child development.

For all general inquiries, please contact the main office at:

Child Development Institute
197 Euclid Ave.
Toronto, Ontario M6J 2J8
Tel: 416-603-1827
Fax: 416-603-6655
Email: mail@childdevelop.ca

www.childdevelop.ca

Ontario Early Years Centres

Ontario Early Years Centres are places where parents and caregivers can take part with their children in a range of programs and activities, get answers to questions, get information about programs and services that are available for young children, talk to early years professionals, as well as other parents and caregivers in

the community. If you have a question about your child's development, or want to know how to get information or services for children up to the age of six, please call or visit your Ontario Early Years Centre in your community.

For a complete list of locations:

Call the INFO line:
Toll-free: 1-866-821-7770
TTY: 1-800-387-5559

<https://www.ontario.ca/page/find-earlyon-child-and-family-centre>

Respite services

Enhanced Respite Care

This is a grant to help families caring for a medically fragile child who depends on a technological device, and/or requires care all day and night, including frequent or time-consuming caregiver intervention and monitoring on a 24 hour basis. Eligibility is determined by the local Community Care Access Center (CCAC).

<http://www.children.gov.on.ca/htdocs/English/specialneeds/respice.aspx>

Transportation

Accessible Parking Permit

This permit entitles a vehicle to be parked in a designated 'accessible parking' space.

An accessible parking permit will be issued to an individual if one of the following eligibility criteria apply:

- Cannot walk without assistance of another person or a brace, cane, crutch, a limb prosthetic device or similar assistive device or who requires the assistance of a wheelchair.
- Suffers from lung disease to such an extent that forced expiratory volume in one second is less than one litre.
- Portable oxygen is a medical necessity.
- Cardiovascular disease impairment classified as Class III or Class IV to standards accepted by the American Heart Association or Class III or IV according to the Canadian Cardiovascular Standard.
- Severely limited in the ability to walk due to an arthritic, neurological, musculoskeletal, or orthopaedic condition.

- Visual acuity is 20/200 or poorer in the better eye with or without corrective lenses or whose greatest diameter of the field of vision in both eyes is 20 degrees or less.
- Condition(s) or functional impairment that severely limits his or her mobility.

<https://www.ontario.ca/page/get-accessible-parking-permit>

OHIP+

OHIP+ makes more than 4,400 drug products free for anyone age 24 years or younger who is not covered by a private plan. Anyone 24 years and under who has OHIP coverage and is not covered by a private plan is covered by OHIP+. You do not have to enroll or register to access OHIP+ coverage.

OHIP+ coverage will stop on your 25th birthday or if you become covered by a private plan, but you may qualify for other financial help with prescription drug costs.

If you have coverage through a private plan, but your household still has significant out-of-pocket costs, you can apply for additional financial support through the Trillium Drug Program. The Trillium Drug Program is available to all OHIP-insured Ontarians who have high prescription drug costs compared to their household income.

<http://www.health.gov.on.ca/en/pro/programs/drugs/ohipplus/>

Exceptional Access Program

The Exceptional Access Program (EAP) provides patients access to drugs not listed on the ODB Formulary, or where no listed alternative is available. In this case, you can get help paying for it when you qualify for the Exceptional Access Program. Children and youth with no private plan and an approved EAP request are fully covered for the cost of their medications under OHIP+.

<https://www.ontario.ca/page/applying-exceptional-access-program#section-0>

If you have immediate questions or concerns regarding the EAP, please contact OHIPplus@ontario.ca.

Northern Travel Grant

Travel grants are funded by the Ministry of Health and Long-Term Care to help defray the transportation

costs for eligible residents of Northern Ontario who must travel long distances within Ontario or to Manitoba to receive medically needed insured specialty services that are not available locally.

For more information:

Ministry INFO line:

1-866-532-3161 (Toll-free in Ontario only)

TTY: 1-800-387-5559

To download a copy of the application visit:

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

Provincial resources—Prince Edward Island

Financial resources

East Coast Fund

East Coast Fund is accessed by a social worker at SickKids Hospital for families from the East Coast undergoing bone marrow transplant in Toronto. It can assist with expenses related to travel and stay in Toronto. Connect with a SickKids social worker for application to this fund.

The Catastrophic Drug Program

The Catastrophic Drug Program provides assistance to Islanders whose eligible prescription drug costs are affecting their household's ability to maintain life essentials. Through this new program Islanders will have their annual out-of-pocket drug costs for eligible prescription medications capped at an amount not exceeding a set percentage of their household income, referred to as 'household cap'.

<https://www.princeedwardisland.ca/en/information/health-pei/catastrophic-drug-program>

Family Health Benefit Drug Program

Family Health Benefit Drug Program covers approved prescription medications for children under 18 and dependent students who are still registered as a full-time student and under the age of 25. Coverage is dependent on income level and number of dependents.

<https://www.princeedwardisland.ca/en/information/health-pei/family-health-benefit-drug-program>

High Cost Drug Program

High Cost Drug Program provides assistance to Islanders for the purchase of approved high cost drugs.

All medications have specific medical criteria that must be met before coverage will be approved.

<https://www.princeedwardisland.ca/en/information/health-pei/high-cost-drug-program>

AccessAbility Supports

The Disability Support Program has expanded and is now called **AccessAbility Supports**. New supports offer more and better assistance to Islanders living with disabilities. Support is provided in the following five areas: Personal Support, Housing Support, Community Support, Caregiver Support, and Financial Support.

<https://www.princeedwardisland.ca/en/information/social-development-and-housing/accessability-supports>

Transportation

The Medical Transportation Assistance Program (MTAP)

The Medical Transportation Assistance Program provides financial assistance to beneficiaries of the Medical Care Plan (MCP) 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 bus services, and taxis when used in conjunction with commercial air travel.

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

Provincial resources—Quebec

Accommodation

Ronald McDonald House Montreal

5800 Hudson Road

Montreal, Quebec H3S 2G5

Tel: 514-731-2871

www.manoirmontreal.qc.ca

Financial resources

Medication Plan

For families that do not have private drug coverage, this public provides free medication for children under the age of 18 years.

<http://www.ramq.gouv.qc.ca/en/citizens/prescription-drug-insurance/Pages/prescription-drug-insurance.aspx>

Sun Youth/Jeunesse au Soleil

Sun Youth is an organization that provides financial assistance with medication, heating, food, school supplies and recreation programs including providing bicycles, camp and sports programs.

4251 Saint-Urbain, Montreal
Quebec, Canada H2W 1V6

www.sunyouthorg.com

Supplement of the Handicapped Child

This provides financial assistance for families to help with the care and education of a handicapped child. The handicap must significantly limit the child in carrying out daily activities for a period expected to last for at least 1 year. It provides non-taxable \$185 a month, for all children who meet the eligibility criteria.

http://www.rrq.gouv.qc.ca/en/programmes/soutien_enfants/supplement/Pages/supplement.aspx

APIQ - Association des Patients Immunodéficients du Québec

The Association of Quebec immunocompromised patients (APIQ) is a non-profit organization comprised of patients with immunodeficiencies and patients with hereditary angioedema (HAE), their families and health professionals concerned with these diseases. Their mission is to contribute to improving the health and quality of life for people with immune deficiencies Association immunocompromised patients Québec aims.

<http://www.cipo-apiq.ca/fr/index.php>

Acknowledgments

The author would like to thank and acknowledge Social Workers from the PI Social Work Network

that contributed to their respective Provincial Guides; Susan Ng, MSW, RSW, Alberta Children's Hospital, Laurie Weir, MSW, RSW, BC Children's Hospital, Cindy Falconer, BA, BSW, Winnipeg Health Science Center, Jacklynn Pidduck, MSW, RSW, IWK Health Centre, Linda Blanchette, MSW, Social Worker, Montreal Children's Hospital, Geneviève Rabouin, BSW, Social Worker, Sainte-Justine's Hospital & Suzanne Laplante, BSW, Social Worker, Sainte-Justine's Hospital.

Funding

This resource guide is compiled by Immunodeficiency Canada with generous support from Grifols Canada and Takeda Canada.

Content statement

The descriptions of the programs and resources within this document are provided directly from the websites/links cited.

Disclaimer

Information in the pages of the *Canadian Resources for individuals and families affected by Primary Immunodeficiency* are of a general nature, are subject to change without notice and are not intended to be relied on by readers as advice in any particular matter. The information is believed to be accurate and complete, but the Immunodeficiency Canada cannot guarantee that it will remain accurate or complete or that it will be current at all times. Immunodeficiency Canada is not responsible for direct, indirect, special or consequential damages, howsoever caused, arising out of the use of this Resource for individuals and families affected by primary immunodeficiency.