



NOVA SCOTIA RESOURCES

For individuals and families affected by
Primary Immunodeficiency (PI)



Immunodeficiency
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Canada

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by Primary Immunodeficiency (PI)

Compiled by:

Wendy Shama, MSW, RSW, Social Worker, SickKids & Immunodeficiency Canada

Jacklynn Pidduck, MSW, RSW, IWK Health Centre

Karthika Yoganathan, B.Sc., Immunodeficiency Canada

Richard Thompson, CFRE, Chief Executive Officer, Immunodeficiency Canada

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Patient Support, Education and Research for a Cure for Primary Immunodeficiency
415 Yonge Street - Suite 1604, Toronto, Ontario M5B 2E7
Tel 416-964-3434 Fax 416-964-6594 Email contactus@immunodeficiency.ca
www.immunodeficiency.ca Charitable Registration # 87276 0897 RR0001

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Provincial Resources

Accommodation

Ronald McDonald House Atlantic Canada
1133 Tower Road
Halifax, NS B3H 2Y7
Phone: 902-429-4044
www.rmhatlantic.ca

Halifax Haven
5897 Inglis Street
Halifax, NS B3H 1K7
Canada

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.
Phone: (902) 421-1650

Capital District Health Authority provides a listing of places to stay in Halifax
<http://www.cdha.nshealth.ca/patients-clients-visitors/places-stay>

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

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 100km 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.
http://irvingoil.com/in_the_community/our_community_programs/fuel_the_care/

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

Nova Scotia Pharmacare Options

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 (eg. 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/>

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.

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 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.

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.

www.cra.gc.ca/cdb

Compassionate Care

Compassionate care benefits may be paid up to a maximum of 6 weeks to a person who has to be absent from work to provide care or support to a gravely ill family member at risk of dying within 26 weeks. Unemployed persons on EI can also ask for this type of benefits. For more information and complete details: Toll-Free: 1 800 206-7218

Website: http://www.hrsdc.gc.ca/en/ei/types/compassionate_care.shtml

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; Form can also be downloaded from the CRA Website: www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html.

Employment Insurance Special Benefits for Parents of Critically Ill Children

You can receive Employment Insurance (EI) special benefits for Parents of Critically Ill Children (PCIC) for up to 35 weeks if you have to be absent from work to provide care or support to your critically ill or injured child. If you are unemployed and already receiving EI benefits, you can also apply for the PCIC benefit. To be eligible for the PCIC benefit, you must be able to show

that: your regular weekly earnings from work have decreased by more than 40% because you need to provide care or support to your critically ill or injured child, you have accumulated 600 insured hours of work in the 52 weeks prior to the start of your claim, or since the start of your last claim, whichever is shorter (this period is called the qualifying period) you are the parent of a child who is critically ill or injured your child is under 18 years of age at the time the 52-week window during which PCIC benefits can be paid opens (based on the date the specialist medical doctor states that your child became critically ill or injured).

For more information, complete details, and forms:

<http://www.servicecanada.gc.ca/eng/sc/ei/pcic/index.shtml>

Family Caregiver Tax 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.

Website: <http://www.cra-arc.gc.ca/gncy/bdgt/2011/qa02-eng.html>

Medical Expenses Tax Credit

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

Website: www.cra.gc.ca

Programs & 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.

Website: www.bigbrothersbigsisters.ca

Cipo – Canadian Immunodeficiencies Patient Organization

CIPO is a volunteer based registered charity. CIPO has six regional Chapters in Canada that hold regular meetings and offer services to patients such as providing literature, advocacy, organizing educational events, and referrals.

<http://www.cipo.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.

Website: www.easterseals.ca

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.

Website: www.primaryimmune.org/idf.htm

Jeffrey Modell Foundation - Friends of John for Life Kids Wish Fund

"Friends of John for Life Kids Wish Fund" is a special "set aside" fund by the Jeffrey Modell Foundation. The fund is designed simply to bring joy and happiness to the lives of kids with immune deficiencies. The fund sponsors tickets for sporting events, concerts, the theatre, days at the zoo, the circus and more. These funds are not for research, doctors, or administration.

Website: www.jmfworld.com/howtohelp/friends.cfm

Canada Medic Alert Foundation

Canada Medic Alert 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), **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>

The Children's Wish Foundation

Child may only have ONE wish either through Children's Wish, Make –a-Wish, or Starlight Foundation

The Children's Wish Foundation is a uniquely Canadian charity that helps Canadian children, families and communities grants wishes to children with high risk and life threatening illnesses.

Website: www.childrenswish.ca

Make-A-Wish Canada

Child may only have ONE wish either through Children's Wish, Make –a-Wish, or Starlight Foundation

The mission of Make-A-Wish® Canada is to grant the wishes of children with life-threatening medical conditions to enrich the human experience with hope, strength and joy.

Website: www.makeawish.ca

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.

Website: 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.

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

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.

Website: www.songsoflove.org

Starlight Children's Foundation Canada

Child may only have ONE wish either through Children's Wish, Make –a-Wish, or Starlight Foundation

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.

Website: www.starlightcanada.org

Young Minds Program – Children's Wish International

Young Minds is a wish program for children who have been diagnosed with a life-threatening illness and are under the age of three, or whose cognitive level is under the age of three. The child must NOT have had a wish fulfilled by another organization. A child is able to choose a package gift of a TV/DVD player, CD music collection, toys and dolls, comfort station with rocker, or activity assortment.

Website: www.childrenswish.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.

Website: <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.

Website: www.hopeair.org

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.

Website: www.achildsvoicefoundation.com/AH-ABOUTUS.HTM

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.

Website: 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.

Website www.immunodeficiency.ca

Online Resources Guide for individuals and families affected by Primary Immunodeficiency

Individual Stories

Newsletters (current and past issues)

In print What is Primary Immunodeficiency pamphlet?

10 Warning Signs for children and adults flyer

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.

If you have comments or suggestions on *Resources for individuals and families affected by Primary Immunodeficiency* please forward them to contactus@immunodeficiency.ca

or mail to:

Immunodeficiency Canada

Suite 1604

415 Yonge Street

Toronto, Ontario M5B 2E7

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