



RESOURCES

for individuals and families affected by Primary Immunodeficiency (PI)

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Immunodeficiency
Canada
Immunodéficience
Canada

Patient Support, Education and Research for a Cure for Primary Immunodeficiency
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Contents

	Page
Accommodation	
Ronald McDonald House Charities of Canada.....	3
Toronto Ronald McDonald House.....	3
Dental Services	
Children in Need of Dental Program (CINOT)	3
Financial Resources	
Assistance for Children with Severe Disabilities (ACSD)	4
Assistive Devices Program (ADP).....	4
Child Disability Benefit	4
Compassionate Care Benefits	4
Disability Tax Credit.....	4
Employment Insurance Special Benefits for Parents of Critically Ill Children.....	5
Family Caregiver Tax Credit	5
Jennifer Ashleigh Foundation	5
Easter Seals Incontinence Supplies Grant.....	5
Medical Expenses Tax Credit	6
Special Services at Home (SSAH).....	6
Trillium Drug Program (TDP)	6
Programs and Services	
Big Brothers and Big Sisters of Canada.....	6
Child Development Institute	6
Easter Seals Canada	7
Immune Deficiency Foundation.....	7
Jeffrey Modell Foundation—Friends of John for Life Kids Wish Fund	7
Kids Help Phone	8
Make-A-Wish Canada.....	8
National Organization for Rare Disorders	8
Ontario Early Years Centres	8
Primary Immunodeficiency Resource Centre	9
Songs of Love	9
Starlight Starbright Children’s Foundation.....	9
The Children’s Wish Foundation.....	9
Young Minds Program—Children’s Wish International.....	10
Respite Services	
Enhanced Respite Care	10
Respite Services	10
Transportation	
Accessible Parking Permit	10
Air Canada Kids Horizon Program.....	11
Hope Air.....	11
Northern Travel Grant.....	11
Wigs	
Angel Hair for Kids.....	11
Wigs for Kids	11
Immunodeficiency Canada	
Financial Assistance, Publications & Social Support for patients.....	12

Accommodation

Ronald McDonald House Charities of Canada

RMHC offers a helping hand and strives to improve the quality of life for children living with serious and/or life-threatening illnesses or disabilities. Ronald McDonald House provides a home-away-from-home for families of seriously ill children being treated at a nearby children's hospital.

For more information:

1 McDonald's Place

Toronto, Ontario

M3C 3L4

Tel: 1-800-387-8808

Fax: (416) 446-3762

Website: <https://www.rmhc.ca>

Toronto Ronald McDonald House

The mission of Toronto's Ronald McDonald House is to enhance the quality of life for out-of-town families with seriously ill children through a caring and supportive 'home away from home'. Families must live a minimum of 70km from the house and have a child receiving medical treatment for serious illness at Toronto Hospital for Sick Children or another area hospital.

For more information:

26 Gerrard Street East

Toronto, Ontario

M5B1G3

Tel: (416) 977-0458

Website: 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: 8:30AM-5:00PM

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 \$420 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 ON M7A 1R3
Toll Free: 1-866-821-7770
TTY: 1-800-387-5559
Website: www.gov.on.ca/mcys

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

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.

Website: www.cra.gc.ca/cdb

Compassionate Care Benefits

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>

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.

Jennifer Ashleigh Foundation

10800 Concession 5

Uxbridge, ON L9P 1R1

Tel: (905) 852-1799

Website: www.jenniferashleigh.org

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 six 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, ON M3C 3N6

Tel: 1-800-668-6252 ext 314

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

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.

Ministry of Children and Youth Services

Client Services Unit

900 Bay Street, M1-57 Macdonald Block

Toronto ON M7A 1R3

Toll Free: 1-866-821-7770

TTY: 1-800-387-5559

Website: www.gov.on.ca/mcys

Trillium Drug Program (TDP)

The Trillium Drug Program (TDP) is intended for Ontario residents who have a valid Ontario Health Card and who have high prescription drug costs in relation to their net household income.

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

Website: www.health.gov.on.ca/english/public/pub/drugs/trillium.html

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.

Big Brothers Big Sisters of Canada

3228 South Service Road, Suite 113E

Burlington, Ontario L7N 3H8

Tel: 905-639-0461

Toll free: 800-263-9133

Fax: 905-639-0124

Website: www.bigbrothersbigsisters.ca

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 our 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
Website: www.childdevelop.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.

For more information:
90 Ellington Ave. East
Toronto, ON
Suite 208
M4P 2Y3
Tel: 416-932-8382
Fax: 416-932-9844
Email: info@easterseals.ca
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.

40 W. Chesapeake Ave. Suite 308
Towson, Maryland, 21204
Tel: 1-800-296-4433
Email: idf@primaryimmune.org
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.

747 Third Avenue
New York, New York, 10017
Tel: 1-866-463-6474
Fax: (212) 764-4180
Email: info@jmfworld.org
Website: www.jmfworld.com/howtohelp/friends.cfm

Kids Help Phone

The Kids Help Phone mission is to improve the well-being of Canadian children and youth by providing them anonymous and confidential professional counseling, referrals, and information through technologically-based communications media.

For more information:
National Office, Kids Help Phone
300-439 University Ave.
TO, ON, M5G 1Y8
Tel: 416-586-5437
Fax: 416-586-0651
Email: info@kidshelpphone.ca

If you are a child or teenager and need to contact Kids Help Phone, please call 1-800-668-6868 or visit Website: www.kidshelpphone.ca .

Make-A-Wish Canada

Make-A-Wish Canada is part of the largest not-for-profit wish granting organization in the world, serving 30 countries with international affiliates on five continents. Since inception in 1980, Make-A-Wish has helped make over 200,000 wishes come true for children around the world. Their mission is to grant wishes to create hope and happiness for children with life-threatening illnesses.

For more information:
Make-a-Wish Foundation
4211 Yonge Street, Suite 521
Toronto, Ontario
M2P 2A9
Toll Free: 1-888-822-9474
Tel: 416-224-9474
Fax: 416-224-8795
Email: nationaloffice@makeawish.ca
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.

For more information:
55 Kenosia Avenue, P.O. Box 1968
Danbury, Connecticut, 06813-1968
Tel: 1-800-999-6673
Fax: (203) 798-2291
Email: orphan@rarediseases.org
Website: www.rarediseases.org

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

Website: www.ontarioearlyyears.ca/oeyc/en/Location/Map.htm

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.

Songs of Love Foundation

P.O Box 750809

Forest Hills, NY 11375

Tel: 1-800-960-7664

Email: info@songslove.org

Website: www.songslove.org

To request a song: <http://www.songslove.org/flash/request.htm>

Starlight Starbright Children's Foundation

Starlight Starbright Children's Foundation is a nonprofit 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.

For more information:

2770 14th Avenue Suite # 100

Markham, ON L3R 0J1

Tel: 905-752-7827

Fax: 905-752-7828

Website: www.slsbcanada.org

The Children's Wish Foundation

The Children's Wish Foundation grants wishes to children with high risk and life threatening illnesses. Please note: children may have only one wish EITHER through Starlight or through Children's Wish.

For more information:

The Children's Wish Foundation of Canada

350 - 1101 Kingston Rd, Pickering, ON, L1V 1B5

Tel: 905-839-8882 Fax: 905-839-3745

Toll free: 1-800-700-4437

Website: www.childrenswish.ca

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 either a TV/DVD player, CD music collection, toys and dolls, comfort station with rocker, or activity assortment.

For more information:

Children’s Wish Foundation International

P.O. Box 28785 Atlanta, GA, 30358

Toll Free: 1-800-393-9474

Website: www.childrenswish.org

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).

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

Respite Services:

Respite Services is a central service with information and referral for respite services throughout Ontario. The service is provided by the Ministry of Finance, Ministry of Community and Social Services and the Ministry of Children and Youth Services.

Website: http://www.respiteservices.com/Ontario/index_e.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 lower 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.

Website: www.ontario.ca

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.

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.

Proctor & Gamble Building
4711 Yonge St.
North York, ON M2N 6K8
Tel: 416-222-6335
Toll free: 1-877-346-4673
Fax: 416-222-6930
Email: mail@hopeair.org
Website: www.hopeair.org

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:

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

Wigs

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.

Tel: 905-274-3434

Toll Free: 1-888-837-3354

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, P.O. Box 38540, 3299 Bayview Avenue, Toronto, Ontario, M2K 2Y5

This resource guide is made possible by the generous sponsorship by:

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GRIFOLS

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Information in the pages of the Immunodeficiency Canada's *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*.