

A GUIDE FOR PARENTS



# CEREBRAL PALSY RESOURCE TOOLKIT

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**Pacific Medical**  **Law**

M E D I C A L M A L P R A C T I C E

We are here to help.



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Parents of a child with cerebral palsy often experience a great deal of uncertainty about their child's future. They also have significant emotional, physical and financial demands placed on them to provide for their child's needs. Here is a list of organizations that may provide some help.

You may also wish to give us a call. We can help connect individuals and families with the resources and services they need, and we would be happy to answer any questions you may have.

# ADVOCACY & SUPPORT

## **Birth Injury Lawyers' Alliance of Canada**

The Birth Injury Lawyers' Alliance of Canada (BILA) was formed in 2016 by a group of lawyers from across Canada with considerable experience in birth injury cases to promote the effective representation of children and families affected by avoidable injuries occurring at or around the time of birth.

## **The Cerebral Palsy Association of BC**

CPABC is a non-profit organization that is committed to making a Life Without Limits for people with cerebral palsy and other disabilities by providing support, education and information throughout BC.

## **The Voice of the Cerebral Palsied of Greater Vancouver**

VCP is a non-profit organization which focuses on advocacy and education for adults with cerebral palsy.

## **Inclusion BC**

Formally the BC Association for Community Living, this non-profit organization advocates for the rights and opportunities of people with intellectual and developmental disabilities and their families through building awareness, inspiring action and advancing rights, responsibilities and social justice.

## **Family Support Institute of BC**

FSI is a provincial non-profit society committed to supporting families who have a family member with a disability. FSI's supports and services are free to any family!

## **Family Support Services (Developmental Disabilities Association)**

Family Support Services provides information and support to families with children with developmental disabilities, as well as caregiver matching for respite care.

## **Disability Alliance BC**

Disability Alliance BC supports people with disabilities through their direct services, community partnerships, advocacy, research and publications.

## **WorkBC**

WorkBC helps individuals with disabilities explore education and career options including connecting them to services and funding opportunities designed to support people with disabilities.

## **Shriner's Hospitals for Children**

Shriner's Hospital for Children is a non-profit health care system dedicated to improving the lives of children with neuromuscular conditions and other special health needs by providing pediatric specialty care, innovative research and outstanding teaching programs.

## **The Family Support & Resource Centre (BC Children's Hospital)**

The Family Support & Resource Centre is a community space and library that provides a unique collection of books, videos, journals, board games, curricula and various educational props and materials designed for children with disabilities and the adults who support them.

## **Supported Child Development (BC Centre for Ability)**

Supported Child Development provides support to childcare staff, families and their children in license daycare, preschool or out of school care programs in Vancouver and Burnaby. Working with daycares, preschools, family daycares and out of school care programs, SDC provides consultation services and extra staffing assistance to ensure inclusive practices for children who have a demonstrated the need for extra support.

## **Convention on the Rights of Persons with Disabilities (United Nations)**

The CRPD is an international human rights treaty intended to protect the right of all persons with disabilities to enjoy all human rights and fundamental freedoms. It also identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights. Parties to the Convention (including Canada) are required to promote, protect and ensure the rights of persons with disabilities.

## **Individual Education Plans (British Columbia Confederation of Parent Advisory Councils)**

This is an informative guide dealing with the development of IEPs for children with disabilities in the public-school system.

# RESEARCH & INFORMATION

## **Cerebral Palsy Registry (BC Children's Hospital)**

The Cerebral Palsy Registry is a confidential, nationwide collection of information about people with cerebral palsy in Canada; the first of its kind in North America. The aim of the registry is to further understand the risk factors and causes of CP, how often children are diagnosed and where they live, as well as to better understand parents' perspectives on their child's care and how services are provided to them.

## **Kids Brain Health Network**

KBHN (formally NeuroDevNet) is a national network of researchers and health professionals who fund collaborative research, train the next generation of developmental neuroscientists and mobilize the knowledge they generate in order to help children with neurodisabilities and their families.

## **CanChild (McMaster University)**

CanChild is a non-profit research and education centre located within the School of Rehabilitation Science at McMaster University focused on children and youth with disabilities and their families. CanChild creates alliances between families, world-class scientists and established research organizations within Canada and internationally.

## **The Cerebral Palsy Foundation**

The Cerebral Palsy Foundation is a non-profit organization dedicated to funding research and educational activities directly relevant to discovering the cause, cure and evidence-based care for those with cerebral palsy and related developmental disabilities.

## **Birth Injury Lawsuits: A Parent's Guide (BILA)**

Written by members of the Birth Injury Lawyers' Association of Canada, this guide is a helpful introduction and overview of the medical malpractice process.

# FUNDING

## **At Home Program (AHP)**

Assists families with the costs of caring for a child with severe disabilities at home; including providing funding to access respite services and medical items and services.

## **Variety: The Children's Charity Grants**

Variety provides funding through grants to children with special needs for medical care and services, mobility equipment, specialized therapies, education and experiences. Their aim is to fill the gaps which are not covered by government programs, healthcare or private health plans.

## **Campership Program (CPABC)**

The Cerebral Palsy Association of BC (CPABC) provide financial assistance to allow individuals of all ages to a special needs camp of their choice in BC. This includes funding to be used towards partial camp fees, transportation and attendant care costs.

## **The Jason & Rand Fund (CPABC)**

Named after Jason Cole and Rand Surbey, friends and adventurers living with cerebral palsy, this subsidy provided through CPABC to assist the purchasing of assistive devices including communication and writing aids, orthotic devices, home accessibility aids, as well as vision and hearing aids.

## **Education Bursaries (CPABC)**

A bursary jointly funded by CPABC and the Kinsmen Foundation financially assisting BC students (17-years of age and older) wishing to attend post-secondary education in the next year.

## **The Lisa Huus Memorial Fund Bursary**

A bursary established in memory of Lisa Pauline Huus, sociology student at the University of Victoria, which provides funding for persons with disabilities wishing to begin or continue post-secondary education at the University of Victoria or other accredited post-secondary institutions in BC. The bursary may be used towards items including tuition fees, textbooks, equipment, transportation, residence or support worker costs.

### **Disability Credit Canada Scholarship for Canadian Students with Disabilities**

The DCCI Scholarship for Canadian Students with Disabilities financially assists Canadian students with disabilities who are currently registered in a post-secondary program in health care, criminal justice or community and social services at an accredited Canadian education institution.

### **The Janna Epp Bursary (Pacific Medical Law)**

Created in honor of Janna Epp, a beautiful and determined young girl with cerebral palsy, Pacific Medical Law provides financial assistance towards the care, therapy and recreation activities of a child with cerebral palsy.

### **The Jennifer and Gregory Louie Foundation Grant**

The JGL Foundation provides grants to individuals with cerebral palsy to financially assist with services such as physical and occupational therapy, as well as for assistive technology and equipment.

### **BC Rehabilitation Foundation Fund (Vancouver Foundation)**

BC Rehab financially supports people with disabilities through education, research, arts, recreation and wellness programs. This fund also allows individuals to purchase personal mobility equipment and other items which will allow them to thrive, participate and contribute in their communities.

### **Fuel Tax Refund (BC Government)**

The fuel tax refund program allows individuals with qualifying disabilities to request a refund of the provincial motor fuel tax you pay when purchasing fuel in BC.

### **Disability Assistance (BC Government)**

Disability assistance helps individuals with disabilities who are in need of financial or health support.

### **Bear Essentials (Children's Health Foundation of Vancouver Island & Help Fill A Dream)**

Bear Essentials supports Vancouver Island children with medical conditions, health challenges and disabilities to cover travel costs associated with receiving health care, medical equipment and therapy.

### **Home Adaptations for Independence (BC Housing)**

Home Adaptations for Independence (HAFI) provides grants to low-income households for individuals with disabilities or families with a member who has disabilities to complete home adaptations to support accessibility and promote safe and independent living.

### **Assistive Devices Program (March of Dimes Canada)**

The Assistive Devices Program from March of Dimes Canada financially assists adults with physical disabilities to purchase, repair and maintain assistive devices to increase their mobility and functional independence. The program may also help to connect individuals with additional funding sources.

### **The Neil Squire Society**

Named in honour of Neil Squire, a young man left a brain-stem tetraplegic after a car crash, the Neil Squire Society creates affordable assistive technology devices that give people with disabilities greater control over their lives. They also offer programs that teach people with disabilities how to use technology and succeed at home and in the workplace.

### **Community Living BC**

CLBC is a crown corporation that works with individuals, families, service providers, community and government partners to fund supports and services to adults with developmental disabilities, as well as those diagnosed with ASD or FASD.

### **Registered Disability Savings Plan (Federal Government)**

A registered disability savings plan (RDSP) is a savings plan that is intended to help parents and others save for the long term financial security of a person who is eligible for the disability tax credit (DTC).

### **The At Home Program (Ministry of Children and Family Development)**

This is a government program which assists parents with the costs of caring for a child with severe disabilities at home through a range of health supports and services.

# THERAPY & RECREATION

## **The BC Association for Child Development and Intervention**

BCACDI is a provincial association of agencies that provide child development and therapy services to children and youth with special needs and their families in BC.

## **BC Centre for Ability**

The BC Centre for Ability is a government funded program providing therapy services (including occupational, physiotherapy and speech language therapy) and support programs for children with disabilities.

## **The Infant Development Program (Developmental Disabilities Association)**

The IDP is a family-centered, home based, consultative program serving children from birth to age three who are at risk for developmental delays, are experiencing a delay or have a diagnosis. Services include home visits to encourage progress, developmental assessments, physiotherapy, parent-child groups and resource lending.

## **Sunny Hill Health Centre for Children (BC Children's Hospital)**

The Sunny Hill Health Centre for Children provides specialized development and rehabilitation services to BC children and youth and their families.

## **Adapted Yoga (Cerebral Palsy Association of BC)**

Adapted yoga offers a safe, calm environment for people with physical disabilities to practice meditative breathing and movement in Vancouver, Victoria and Kelowna. This program offered by CPABC is free and inclusive!

## **Art Without Limits (Cerebral Palsy Association of BC)**

This free program offered by CPABC in Vancouver provides opportunities to children and youth with disabilities to express themselves through various therapeutic artistic mediums.

### **Dance Without Limits (Cerebral Palsy Association of BC)**

Offered for free in Surrey, Victoria and Kelowna by CPABC, Dance Without Limits offers a safe and active environment for children and youth with disabilities to explore dance, creative movement and games.

### **British Columbia Mobility Opportunities Society (BCMOS)**

BCMOS provides accessible hiking and summer paddling programs to people with physical disabilities in the Lower Mainland. The centrepiece of their hiking program is the TrailRider, a custom-built access-all-areas wheelchair that can tackle any terrain.

### **Disabled Sailing Association of British Columbia**

The Disabled Sailing Association of British Columbia offer sailing experiences to anyone ages eight and up out of Jericho Sailing Centre in Vancouver. Their fleet of Martin 16 sailboats are specifically designed to be accessible for all levels of ability and participants range from novices to experienced racers.

### **Disabled Independent Gardeners Association**

By joining DIGA, participants will be supported by staff and volunteers to tend to one of their community gardens plots each growing season. Gardens are accessible, with raised garden beds, accessible paths and access to adaptive gardening tools.

### **Vancouver Adapted Music Society**

VAMS supports and promotes musicians with physical disabilities in the Vancouver area by teaching individuals to make music or sing, record, produce and build performance skills. They operate Canada's only fully accessible recording studio! VAMS seeks to show that disability is not a barrier to creativity.

### **Sportability**

Sportability is a non-profit association which provides physical activity programs (including sledge hockey, boccia, power soccer and CP/Para soccer) for individuals with disability at both recreational and competitive levels.

### **Vancouver Adaptive Snow Sports (VASS)**

VASS is a non-profit society which makes the mountain experience accessible to all through their ski and snowboard programs for persons with disabilities on Grouse, Seymour and Cypress Mountains. Students of all ages, experience levels and disabilities are welcome!

### **BC Wheelchair Sports Association**

BCWSA is the leading organization fostering community and individual excellence through wheelchair sports. They offer programs for wheelchair rugby, track and field and tennis for people with physical disabilities at all levels. BCWSA hosts competitions from the recreational to high performance level.

### **Communication Assistance for Youth and Adults**

CAYA is a provincially funded service run through the Ministry of Social Development and Poverty Reduction. They loan adults aged 19 years and older with severe communication disabilities augmentative or alternative communication (AAC) systems to enable them to create an adult life to the best of their abilities.

### **Access 2 Program (Easter Seals Canada)**

Access 2 is a membership program which helps to ensure that entertainment, cultural and recreational opportunities are more available and accessible to Canadians living with disabilities. With over 500 participating partner venues across the country, the Access 2 card allows people with disabilities who require the assistance of a support person to bring their support person to participating facilities for free or at a discounted price.