

Local Resources for New Diagnosis/Newborn to 6 months

Congratulations on the arrival (or future arrival) of your baby!!! The time around a new diagnosis can be very overwhelming; therefore we have highlighted key resources to begin with.

Societies for support:

Greater Victoria Down Syndrome Society (GVDSS)

- The GVDSS membership includes individuals who have Down syndrome, as well as families, friends, advocates, peers, educators, and medical professionals. Together we provide information and understanding about Down syndrome, act as resources and supports for one another, and create a better understanding of diversity. The first year of membership is FREE.
- Find us on Facebook. www.facebook.com and search for GVDSS. This is the best way to
 connect with us! There will be current information about events such as seasonal gatherings,
 Ups club get togethers, etc.
- Please look at our website: www.gvdss.org
- E-mail: info@gvdss.org for further information

Canadian Down Syndrome Society

- www.cdss.ca; they provide new parent packages and education resources all linked to their website.
- A membership to CDSS is included in the membership of GVDSS

Community Living Victoria

- www.communitylivingvictoria.ca
- 3861 Cedar Hill Cross Road, Victoria, BC V8P 2M7
 Phone: (250) 477-7231; Fax: (250) 477-6944
- Lori Frank- Family advocate is a great person to connect with re: resources in the community

Healthcare services:

Medical Genetics at Victoria General Hospital- have a wealth of information about the "why's"

- genetic counselling available
- 1 Hospital Way, Victoria BC V8Z 6R5, Canada
- Phone: 250-727-4461

Pediatrician

There are a number of **pediatricians** in the Greater Victoria area. Referrals to a pediatrician can be made either at the hospital (at birth) or through a family doctor (GP). It is important to have a pediatrician as part of the medical team to monitor the progress of your baby's development. They can case manage the other pediatric specialists who may be needed along the way.

Queen Alexandra Centre for Children's health (QACCH)

2400 Arbutus Rd, Victoria, BC

(250) 519-5390 and ask for Central Intake

- Once your baby is born, a referral for services can be made through central intake- a physician or parent is able to call and make a referral.
- Early Intervention program: provides Infant Development (IDP), Social work, Occupational Therapy (OT), Physical Therapy (PT), and Speech and Language (SLP) services across Greater Victoria and the Gulf Islands for children age 0-5 years old.
- The service providers work together in teams and they will manage the services your family and child requires throughout their growth and development.

Government services:

Disability Tax Credit Certificate:

- www.cra.gc.ca
- Application form can be filled out by GP or pediatrician
- Tax credits can then be deducted on personal taxes yearly
- This certificate must be done before a Registered Disability Savings Plan (RDSP) can be opened.

Other Online Resources/Social Media/Books

As noted above, GVDSS has a Facebook page. www.facebook.com and search for GVDSS.

There are many blogs online that may be helpful to you and your family as they are stories told by those that have been there. Here are a couple of examples that families have connected with.

- www.kellehampton.com: Enjoying the Small Things: a lovely blog of a family whose second child was surprisingly born with Down Syndrome. Kelle Hampton also wrote a memoir called "bloom: finding the beauty in the unexpected" that is available to borrow through the Victoria Public Library. Kelle is located in Florida and has links to resources based in the U.S. if you are interested in additional information.
- www.happysoulproject.com: this is a blog by a mom in Kingston, Ontario with a young daughter with Down Syndrome who had to have heart surgery when only months old.

Books:

"Babies with Down Syndrome: A new parent's guide"- this is a book written by U.S. authors therefore some information does not pertain to Canada but the chapters in the beginning of the book are a helpful introduction to parenting a baby with DS and all of the emotions that go along with it. A copy is in the GVDSS library or can be borrowed through Queen Alexandra.

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