

Fetal Cardiac Program Information Package



SickKids® | Labatt Family
Heart Centre

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About the Fetal Cardiology Program at SickKids

The Fetal Cardiac Program is made up of a multidisciplinary team that provides detailed evaluation, counseling and treatment for heart problems in the developing baby during pregnancy. We work closely with family doctors, midwives, community and high-risk obstetricians throughout Ontario, as well as geneticists and other pediatric subspecialists. We partner with Mount Sinai Hospital to provide a range of fetal therapy through the Ontario Fetal Centre.

The Fetal Cardiac Program is a teaching program in affiliation with the University of Toronto.



Front Desk	(416) 813 – 4914
Fetal Cardiology Nurse Coordinators Nathalie Dutil Zoey Katz Lisa Stennett	(416) 813 – 6514 nathalie.dutil@sickkids.ca zoey.katz@sickkids.ca lisa.stennett@sickkids.ca
High Risk Pregnancy Program Mount Sinai	(416) 586 – 8808 Ext. 2.
Cardiac Critical Care Unit (CCCU)	(416) 813 – 6490
4D In-patient Cardiology Ward	(416) 813 – 6901

Professional Roles

Fetal Cardiologist:

The fetal cardiologist is a specialist physician who diagnoses your baby's heart condition. He/she will provide counseling about management of the pregnancy and baby, and describe what to expect throughout pregnancy, infancy, childhood, and beyond. The fetal cardiologist will provide expertise and answer your questions about the medical and surgical management of your baby's heart condition.

Our Fetal Cardiologists:

Lindsay Freud (MD, FASE, FAHA)

Mike Seed (MBBS, MRCPCH, FRCR)

Vitor Guerra (MD, PhD)

Koyelle Papneja (MD, FRCPC, FAAP, FACC)

Sonographer:

Our experienced sonographers perform fetal echocardiograms, which are dedicated ultrasound studies of your baby's heart. They review the studies with the fetal cardiologists to make diagnoses of potential heart problems in your baby.

Clinical Fellow:

A specialist physician completing his/her training in fetal cardiology. He/she may perform the fetal echocardiogram and counsel you on the diagnosis and treatment with the supervision of other staff.

Clinical Nurse Coordinator:

Your clinical nurse coordinator will support you throughout your prenatal journey at SickKids. She will be present for counseling discussions, prepare you for delivery and treatment, coordinate various consults & appointments, check in with you throughout your pregnancy, be your point-person for interim questions or concerns between appointments, and provide you with a tour of the cardiac units where your baby will be. We will ensure you feel adequately prepared for having a baby with a prenatal diagnosis of congenital heart disease.

Contact:

Nurse phone number: (416) 813-6514

Nathalie Dutil (RN BScN): nathalie.dutil@sickkids.ca

Zoey Katz (RN, MN, BNSc, CpedN(C)): zoey.katz@sickkids.ca

Lisa Stennett (RN BScN): lisa.stennett@sickkids.ca

Resource Navigator:

Resource Navigators are part of the Department of Social Work. They help parents who live out of town arrange accommodations near SickKids for when their baby will be admitted to hospital. They can also help parents navigate parental leaves and caregiver benefits.

Contact: resource.navigation@sickkids.ca

Social Worker:

Your social worker will help care for you and your needs after your baby is born and may meet you prenatally to start to get to know you and your family. She may help you with coping through admission, financial concerns, difficult medical decision-making, and resource coordination.

Contact:

Mayola Mathew (MSW, RSW): mayola.mathew@sickkids.ca

Heather Telfer (MSW, RSW): heather.telfer@sickkids.ca

Leslie-Ann Valley (MSW, BSW, RSW): Leslie-ann.valley@sickkids.ca

Lactation Consultant:

Your lactation consultant will meet you before your baby is born and prepare you for providing breast milk for your baby if you wish. She will review pumping and provide you with a kit to use while pumping in the hospital. Lactation consultants will be available at your baby's bedside to provide pumping and feeding support after your baby is born.

Breast Pump:

If you are interested in providing breastmilk after delivery, purchasing a breast pump is recommended for use when you are outside of the hospital. Our lactation specialists recommend either the Medela or Ameda brands and to select a double electric traditional breast pump. Please speak to a lactation consultant about rental options.

Contact: lactation.consultants@sickkids.ca

IMPACT (Infant Maternal Perinatal Advanced Care Team):

This is a team made up of doctors and nurses from SickKids and Mount Sinai Hospital. The team meets with families whose babies have received a complex and/or life-threatening cardiac diagnosis before birth. IMPACT works with your other care providers to explore and support your goals of care for all stages of prenatal and postnatal care.

Contact:

Andrea Steadman, IMPACT Clinical Nurse Specialist: andrea.steadman@sinaihealth.ca



Useful Resources

Congenital Heart Defects

[SickKids About Kids Health](#)

Provides easy-to-read information with useful diagrams about various congenital heart defects. Available in several languages.

[Helen B. Taussig Children's Heart Center, Johns Hopkins University - Cove Point Foundation](#)

Includes information about congenital heart disease including anatomy, anomalies, surgeries, and health and nutrition.

[Cincinnati Children's Hospital Heart Centre Encyclopedia](#)

Provides short descriptions of many different congenital heart defects, diseases and cardiac anomalies including signs and symptoms, diagnostic methods and treatment options.

[Conquering CHD](#)

The Education Series on the main page links you to many recent YouTube videos that may be useful as you provide care to your baby with CHD.

[Heart and Stroke Foundation of Canada](#)

A very brief and simple overview of many different congenital heart diseases, their symptoms, diagnoses, and treatment. There are also many downloadable PDFs for convenience.

Parent Support and Coping

SickKids About Kids Health - Supporting yourself as a caregiver

Taken from the SickKids Mental Health Learning Hub, this resource helps you understand the importance of taking care of yourself while caring for your child's condition.

CHD Care Compass

Provides support for parents who are coping with their child's CHD regardless of what stage they are at in their journey.

Children's Heart Network

Resource for parents out of BC Children's Hospital outlining important coping mechanisms for parents of children with CHD.

A Parent's Perspective

Caregivers shared their experience being at SickKids with a child who has CHD.



Scan QR code for the YouTube video-series

Cautious note about social media for support groups. Online social media support groups (such as Facebook groups) can be a tool to read through and share experiences. However, each child's journey is unique, and all information posted should be considered accordingly. We may not recommend the same for your child. Also, please be careful to protect your family's privacy.

Additional Resources for Specific Situations

Single Ventricle Hearts

Support, education, and empowerment for families affected by Single Ventricle Heart Defects. The document is compiled by parents and medical professionals.

*Guide for Parents – go to website – click ‘Newly Diagnosed’ tab – Guides & Toolkits – Single Ventricle Journey Guide

Palliative or Compassionate Care

A resource given to parents to help them cope with finding out that their baby may die before or after birth.



Genetic Syndromes Associated with Congenital Heart Defects

Some congenital heart defects are associated with certain genetic syndromes or changes in the child's DNA. Your fetal cardiologist will discuss genetic screening and testing options with you. If your child has a likely or definite diagnosis of a genetic syndrome, the following resources may be helpful in providing further information.

SickKids Clinical and Metabolic Genetics Department

Down Syndrome

[Down Syndrome Association of Toronto](#)

[National Association for Down Syndrome](#)

Di-George Syndrome / 22q11 Microdeletion Syndrome

[SickKids About Kids Health](#)

[Care Options for Kids](#)

[Mayo Clinic](#)

Other Syndromes

[Williams Syndrome Association](#)

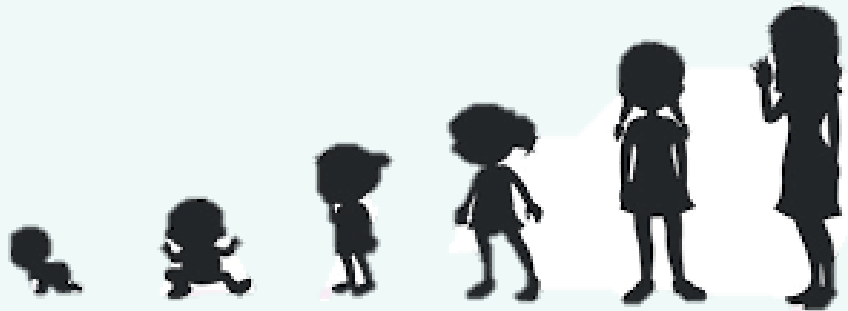
[Noonan Syndrome- Mayo Clinic](#)

Adults Living with Congenital Heart Defects

Patients who have been diagnosed with a congenital heart defect will need lifelong follow-up by a cardiologist. At the age of 18, care will be transitioned to an adult cardiologist.

[Canadian Congenital Heart Alliance](#) - resources for adults with CHD and parents of CHD kids

[Transition from pediatric to adult CHD care](#) - resources for teens/young adults with CHD and their families



Hospital Information

All About SickKids

Labatt Family Heart Centre

About Kids Health

- [Health A-Z](#)
- [YouTube Channel](#) - helpful for visuals, covering many topics.
- [Mental Health Learning hub](#)

Spiritual Care

SickKids Professional Healthcare Spiritual Care Providers offer spiritual and religious care through counsel, connection, companionship as well as a support for religious rites and culture. Please visit the following site for further information and contact details:

Parent Liaison - Critical Care Unit

Amy Zubick is a mother of a child who was diagnosed with CHD and treated in the Sick Kids Cardiac Critical Care Unit (CCCU). She now works in the CCCU, supporting parents through their individual journeys.

Tel: 416-813-8734 | Email: amy.zubick@sickkids.ca

Patient & Family Experience

The Patient & Family Experience team works with patients, families, and staff to advance the delivery of care that is centered on the needs of patients and their families.

- **Family Centre:** Health information, children's books, schooling services, and other resources at the Family Centre.
- **Lived Experience Network:** Formal opportunities for children and families to partner with staff to shape our services and care -

- Play and programming for children and their families in our Family Spaces.
- Interpreter Services for limited English-speaking patients and families, and those who are deaf, deafened, or hard of hearing.
- Legal services for families through the Pro Bono Law Ontario at SickKids program.
- Health equity and cultural competence expertise.
- A safe space to share ideas, comments, or concerns through the Office of Patient and Family Experience
- Spiritual and emotional care to patients, families, and staff through the Spiritual Care department.
- Computers with internet access and internet hook-up for personal laptops available

CPR Classes for Parents – in-person or virtual

Visiting Guidelines

At SickKids, parents are part of their child's care team Check our [website](#) regularly for up-to-date visiting guidelines and information

Check out our [Patient and Family Welcome Guide](#) for more information about planning your stay.

Security

SickKids' Protection Services department has a 24-hour phone line at 416-813-7122. You can call this number if you would like someone to walk with you to your car. For your protection, leave items of value and large amounts of cash at home, or keep them with you at all times. The hospital is not responsible for lost or stolen personal items.

Family Spaces and Programming

Sick Kids offers several [spaces for patients and families](#) to play, relax, and unwind, during a stressful time.

- **[WAV Play Park:](#)** Located on the main floor (near Starbucks) is a supervised play facility for siblings of Sick Kids patients.
 - Located on the main floor, across from Starbucks
 - Open 7 days a week
- **[Ronald McDonald House Charities Toronto Family Rooms](#)**
 - Hospital – 4th floor, Atrium
 - Patient Support Centre – 5th floor

Parking

SickKids' automated parking garage entrance is located on Elm Street and accepts cash and credit cards at one of the pay stations located in each parking lobby when exiting. For hours and rates, please visit the [website](#). All parking ticket and parking pass purchases are final. Refunds are not available. There are no 'in-and-out' privileges for daily parking.

Parent Discount Passes:

H-Pass: SickKids offers a discounted multi-use parking pass (H Pass card) for parents of patients and their frequent visitors. The H Pass is a card that offers a reduced parking rate and allows for in-and-out privileges throughout a 24-hour period. The pass can be shared among family members and the patient's visitors. Please refer to the [Parking webpage](#) for rates and more information.

Parent 1 month pass: Parents can purchase a [discounted 1-month pass](#) from the Parking Office on Level P1. The Parking Office is located on Parking is open daily, including weekends and holidays, from 6 a.m. to 9 p.m. All pay stations also have a customer-service call button available 24 hours a day.

Street Parking and Additional Parking around SickKids

Street parking is available but read the signs carefully. Do not park on nearby streets before 9:30 a.m. or between 3:30 and 6:30 p.m. Do not park in the Emergency driveway or in the driveways off Gerrard Street, Elizabeth Street or University Avenue. Cars will be ticketed and towed away. If you decide not to park at SickKids, there are many parking lots conveniently located around the hospital.

Pediatrician

We recommend finding a pediatrician for your baby. You can find information about all pediatricians in Ontario, including practice addresses, telephone numbers and qualifications on the [College of Physicians & Surgeons \(CPSO\) website](#).

- Select “Advanced Search” and “Pediatrics” as the **specialty**.

If you also need a family doctor, the Ministry of Health has created a website called [Health Care Connect](#) which allows you to register online. They will match you with a healthcare professional accepting patients in your community.



What Should I Bring for my Baby's Hospital Admission?

SickKids provides:

- Diapers
- Blankets, towels, facecloths, linens and gowns
- Breastfeeding supplies and support (access to breast pumps when on-site, containers and labels for breast milk storage, lactation consultants)
- Formula and other feeding supplies (bottles, nipples, soothers, feeding tubes, etc.)

Parents can bring:

- A soft toy, blanket or other comforting measure for the infant
 - You can “wear” a soft toy, small blanket or piece of fabric (bonding square) on you for a few weeks prior to delivery; it will absorb your scent and can be put in baby's crib to promote bonding and comfort
 - Family pictures and drawings from siblings are welcome and a nice way to involve older siblings in the care of the newborn
- Simple clothing, easy to put on (“sleepers” with snaps or buttons down the front, socks & mittens, hats) – note that in CCCU, infants are not usually dressed, only once child is more stable and transferred to 4D/cardiac ward
- Baby wipes if you wish to use them
- Receiving blankets and other linens from home (remember to identify these items and that you will be responsible for their laundry as they will otherwise get lost if mixed with the hospital laundry)
- Their own toiletries, clothes and personal items
- Breastfeeding mothers will need a breast pump when off-site (i.e. home, hotel or alternate accommodations) and a “cooler” type bag with gel

packs to transport the breast milk safely to SickKids (containers and labels are provided by the hospital)

- **A car seat to take your baby home!**



Mount Sinai Resources

[Ontario Fetal Centre](#) has information about:

- Having a baby at Mt. Sinai
- Perinatal Mental Health
- Prenatal Classes
- Visitor Information
- Other Helpful Resources

Community Resources

Benefit Programs

A member of the Resource Navigation team can help you determine if you qualify for these:

- [Employment Insurance \(EI\)](#) – Maternity and Parental Benefits:
Canadian employees are entitled 40-69 weeks of unpaid, job protective leave in the event of the birth of a child. If you have accumulated 600 insurable hours of work in the last 52 weeks, you may qualify for employment insurance (33-55% of your salary) during your maternity and/or parental leave. For more information visit:
- [Ontario Drug Benefit Program](#)
- [Assistance for Children with Special Needs](#)

Accommodations

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."

240 McCaul Street, Toronto, Ontario M5T 1W5

Tel: 416-977-0458

- Private rooms with shared bathrooms for Hospital for Sick Children's families
- Communal kitchen, laundry facilities, internet access

Hotels, Rentals & Accommodations

Finding a place to stay in Toronto is expensive! SickKids has special rates with nearby hotels. Each stay is walking distance to the hospital and parking is available at SickKids with the H-pass. There also other options for accommodations like rentals. For more information, please visit the SickKids website.



- [Short-Term Accommodation Options](#)
- [Long-Term Accommodation Options](#)