

The Selective Dorsal Rhizotomy Experience for CTN Clients

This is a review of information about the provincial Selective Dorsal Rhizotomy Program at Holland Bloorview Kids Rehabilitation Hospital and The Hospital for Sick Children (SickKids), as well as post-surgical rehabilitation through the Children's Treatment Network (CTN).

The Provincial Selective Dorsal Rhizotomy (SDR) Program

One of the most common symptoms of Cerebral Palsy (CP) is increased muscle tone that causes stiffness (also known as spasticity). This can affect movement and cause pain. Selective Dorsal Rhizotomy (SDR) surgery can help permanently reduce spasticity in children with spastic CP. Given that spasticity is only one factor/aspect associated with cerebral palsy, SDR is not recommended for all children with spastic CP. Careful selection for SDR is important to meet client and family goals. Ontario now provides the opportunity for children recommended to have an SDR, to have this done in Toronto through the SDR Program. The SDR Program at Holland Bloorview and SickKids includes an assessment clinic, surgery and post-operative rehabilitation.

Who is eligible for the SDR Program?

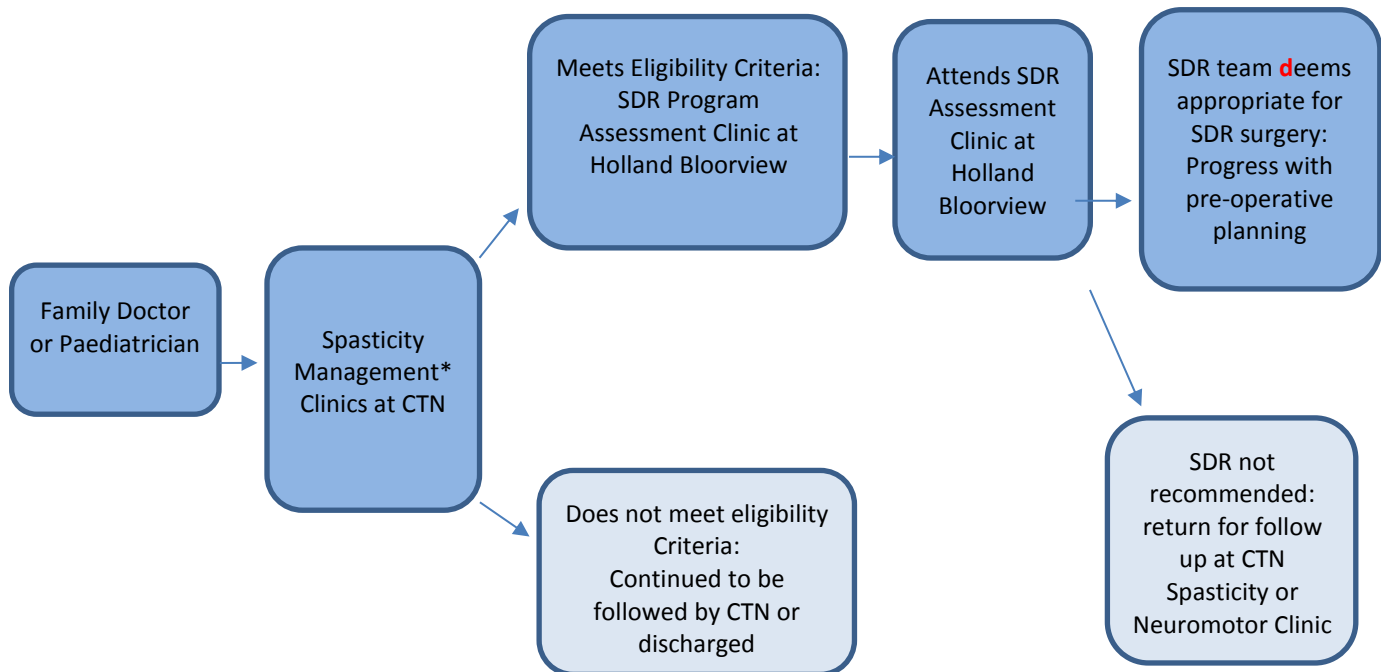
Children in Ontario with Spastic Cerebral Palsy affecting both legs, who are typically between the ages of 4 years and 8 years, and have goals to improve standing, walking or running may be eligible for the SDR Program. There are also specific exclusion criteria as outlined in the Provincial Program such as the presence of dystonia. The Spasticity Management and/or Neuromotor (York only) team at CTN will determine if a child is appropriate for a consult with the Provincial SDR Program at Holland Bloorview and SickKids.

If appropriate, each child is individually assessed by the multi-disciplinary team at Holland Bloorview to evaluate whether the child is a suitable candidate for SDR and to determine the best care pathway and outcomes to meet the child's unique needs and goals.

How can I obtain a referral to the SDR Program for my child?

Families will be referred to the SDR Program assessment clinic at Holland Bloorview through the Spasticity Management and Neuromotor (York only) clinics at CTN. A referral to the SDR Program assessment clinic must come from a physician associated with the Children's Treatment Network. If families are not seen in these clinics they should request a referral to the CTN clinic their family doctor or paediatrician (family doctors and paediatricians not associated with CTN cannot make direct referrals to the SDR program). The SDR Program assessment clinic at Holland Bloorview determines eligibility for SDR surgery.

Families may also discuss their concerns/plans with their therapy team who may help walk them through this process.

Referral Process


*Clients already attending Neuromotor clinic (York only) may be referred directly to HBKRH if appropriate. Clients should not attend neuromotor clinic for the sole purpose of a referral for SDR. All clients attending Neuromotor clinic must meet the Neuromotor clinic criteria.

Who would be my child's medical team?

While going through the SDR Program your family will be supported by your CTN team and the teams at Holland Bloorview and SickKids. Your CTN team may include any healthcare provider involved in your child's regular care (e.g. physiotherapist (PT), occupational therapist (OT), service planning coordinator, physician, etc.). The SDR clinic assessment team at Holland Bloorview and SickKids consists of a multi-disciplinary team that includes a neurosurgeon, orthopedic surgeon, pediatric rehabilitation specialist, PT, OT, and registered nurse.

How does the SDR Program work?

Children who are referred by CTN to the SDR Program assessment clinic at Holland Bloorview may expect the following:

1. An in-depth assessment is completed at the SDR clinic at Holland Bloorview in Toronto to determine if the child is eligible for SDR surgery. SDR assessment clinics are held four-five times per year.

2. If the child is determined eligible for SDR surgery, the family will be offered surgery for their child. If the family agrees with the plan, a surgery date will be scheduled.
3. The child will receive surgery at SickKids and will stay at SickKids as an inpatient for approximately four to five days.*
4. The child will then be transferred to Holland Bloorview for up to three months of intensive inpatient and/or day-patient (outpatient) rehabilitation.*
5. After discharge from Holland Bloorview, the child will then receive PT for up to 12 months post-surgery and OT for up to 3 months through CTN. During this time period, children will also have two follow up assessments at Holland Bloorview in Toronto.*

**For children who are a GMFCS level IV and undergo a SDR in Ontario there will be some variation in the post-surgical plan as determined by the SDR team. Some anticipated changes would be a shorter length of stay at HBKRH (ie. 6 weeks) and a different frequency of community therapy (see below) If you are unclear of your child's GMFCS level please discuss this with your team.*

Therapy after SDR

Children post-SDR will require intensive physiotherapy and occupational therapy to learn and practice new motor patterns resulting from reduced spasticity, and to achieve long-term goals.

If surgery occurs at SickKids, rehabilitation post-SDR is initially carried out at Holland Bloorview (for up to three months post-surgery)*. This allows for increased intensity of rehabilitation during the immediate post-operative period. Upon discharge from Holland Bloorview, the child will be transferred to the CTN team for outpatient therapy.

Here is what you can expect:

Your child's therapist(s) will work with you as a team to set goals and develop a treatment plan to maximize the beneficial effects from the SDR surgery that meets your family's/child's needs. Your consistent involvement and support will be important in making a meaningful and lasting impact. As parents and caregivers, you know your child the best. You know their strengths and abilities, as well as their needs and challenges. Your active participation will be essential in supporting your child in order to reach their targeted therapy goals.

Therapy may occur at a CTN site, in a pool (hydrotherapy), through a home program, or in a group environment. Therapy may be delivered by a physiotherapist, occupational therapist, and/or rehabilitation assistant.

An essential part of therapy is for therapists to coach/teach you & your child the skills and knowledge to perform the therapy activities at home.

- An important factor in meeting therapy goals is the **client/parent follow-through of the home program provided.**
- Participating in **both home and community-based activities** and improving your child's quality of life are a central focus of therapy intervention.

The most appropriate frequency and duration of therapy will be determined by you and your therapists based on your child's individual needs. Your child's progress will be reassessed often. Frequency will change over the course of your child's care to reflect his or her ongoing needs.

Five days to Three Months Post-surgery (at Holland Bloorview):

During inpatient rehabilitation, your child will receive therapy from a PT/PTA (physiotherapy assistant) five times per week and an OT/OTA (occupational therapy assistant) two to three times per week, each for 45 to 60 minute sessions.

In the early recovery stages of SDR surgery, the focus of therapy sessions is on lower and upper extremity strengthening and postural control because of underlying muscle weakness. Underlying muscle weakness becomes evident when spasticity is reduced and may lead to decreased function. Range of motion and positioning are also an early focus of therapy.

Standing, walking and functional mobility activities are gradually introduced as your child's strength and motor control improve, along with progressive independence in completing activities of daily living; all in preparation for return to home and school environments.

** For children GMFCS level IV the length of stay may be different – please speak to your HBKRH team*

Discharge from Holland Bloorview

Once discharged from your inpatient hospital stay, you will be followed by your CTN therapists. Children continue to make functional improvements during the first year post-SDR surgery and the family's active participation is essential. Your child will continue to receive support from CTN in the home and school as required, however, the post-surgical rehabilitation will occur at a CTN site.

**The post-operative course for children who are GMFCS Level IV may develop differently.*

Three to Six Months Post-surgery/Discharge home from HBKR

During this period your child's CTN team will see your child **up to** two times per week for physiotherapy and **up to once per week** for occupational therapy, if required. The therapy may be delivered by a rehabilitation assistant.

The therapy focus will be on strengthening, balance, and walking with emphasis on achieving the highest level of functional mobility and endurance while decreasing walking support. Clients who are able to walk independently prior to surgery are usually able to resume walking independently again between three to six months post-SDR with the potential for improved alignment and efficiency.

***For clients who are GMFCS Level IV post-operative therapy may look different. The CTN team will see your child **up to** two times per week for physiotherapy (to up 6 months) and **up to** once per week for occupational therapy (up to three months), if required. The therapy may be delivered by a rehabilitation assistant. Therapy focus for children with GMFCS IV will be related to any functional goals as determined pre-surgery with the HBKRH team and to increase ease of care.*

Due to a difference in goals children with GMFCS IV may plateau in progress sooner than those who ambulate. Therapy frequency will change based on progress and need.

Six to 12 months Post-surgery

Once your child is six months post-surgery, physiotherapy **may be** available one to two times per week based on the client progression towards goals. Occupational therapy will be provided using a traditional CTN therapy model which can be found on the CTN website: <https://www.ctnsy.ca/Program-Services/Occupational-Therapy-and-Physiotherapy-Services.aspx>

The focus of therapy during this period is to improve walking endurance, static and dynamic balance, and to continue to build strength. Activities are individualized to each child's level of progress and specific functional goals.

For clients at GMFCS IV physiotherapy will be focused on individual goals and **may be available 1/week up to 9 months if there is progress towards the pre-established goals*

One Year Post-surgery

After 12 months, therapy will be provided in a traditional CTN therapy model which can be found on the CTN website: <https://www.ctnsy.ca/Program-Services/Occupational-Therapy-and-Physiotherapy-Services.aspx>

If you have any questions please contact your therapy team.

Summary of Rehabilitation Service post SDR for Children GMFCS I-III.

Time Post Surgery	Frequency of PT Service	Frequency of OT Service
0-3 months	Provided by HBKRH	Provided by HBKRH
3 months or discharge from HBKRH – 6 months	1-2x week depending on need (at CTN site). May be provided by rehabilitation assistant	0-1x a week depending on need (at CTN site). May be provided by rehabilitation assistant
6 to 12 months	1-2x week depending on need (at CTN site). May be provided by rehabilitation assistant	OT per CTN Service model https://www.ctnsy.ca/Program-Services/Occupational-Therapy-and-Physiotherapy-Services.aspx
12 months +	PT per CTN Service model https://www.ctnsy.ca/Program-Services/Occupational-Therapy-and-Physiotherapy-Services.aspx	

*See above notes for children GMFCS Level IV