



# Selective Dorsal Rhizotomy (SDR)

**A guide for parents and caregivers**

## Our Mission

We strive to provide the best possible care for children and adults with spastic cerebral palsy.



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## Selective Dorsal Rhizotomy

A surgical program to provide better mobility to children with cerebral palsy spasticity

### A LIFE-CHANGING PROCEDURE

Many children with cerebral palsy have spasticity, or stiffness in the muscles of their arms, legs and trunk. Spasticity in children can affect movement and the development of walking. Spasticity is harmful in growing children because it can prevent muscle growth and cause muscle contractures and permanent deformities. Spasticity damages muscles and causes loss of the ability to walk in adulthood. It is important to reduce or eliminate spasticity at an early age.

Children who come to St. Louis Children's Hospital benefit from the latest technology and the world's leading neurosurgery specialists.

### HOPE FOR THE FUTURE

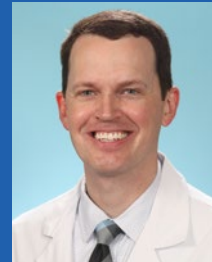
Spasticity in children with cerebral palsy may be treated with physical therapy, oral medications, injections, bracing and orthopedic surgery. Selective dorsal rhizotomy, a neurosurgical procedure, is an additional treatment option. The rhizotomy can reduce spasticity permanently and improve motor activities. When performed at an early age, the rhizotomy can reduce the number of orthopedic operations the child may need. Since 1987, our team has proven the selective dorsal rhizotomy to be a safe and effective surgery.

## A Winning Team

From your first experience with our clinic, you will see the difference the selective dorsal rhizotomy program at St. Louis Children's Hospital offers. We pride ourselves on the close relationship we develop between parents, patients and staff.

St. Louis Children's Hospital follows a multi-disciplinary approach to patient care that involves the expertise of many health care professionals. The team includes physicians, nurses, dietitians, social workers, child life specialists, and physical and occupational therapists. Everyone works together to ensure the best treatment for your child. The family is considered an important member of the team. We work to provide treatment programs that promote understanding, interaction and independence for both your child and your family members.

We also provide coordinated screenings before and after surgery that involve staff members from neurosurgery, physical therapy, orthopedics, neurology, rehabilitation, as well as the patient's own referring physician.



## About Dr. Roland

The procedure is performed by Jarod Roland, MD, Director, Center for Cerebral Palsy Spasticity at St. Louis Children's Hospital, and one of the nation's leading pediatric neurosurgeons.

Learn more about Dr. Roland at [stlouischildrens.org](http://stlouischildrens.org).

## Understanding Muscle Stiffness in Children with Cerebral Palsy

The stiffness of a muscle is called muscle tone. Normally, muscles must have enough tone to maintain posture or movement against the force of gravity, while at the same time providing flexibility and speed of movement. The command to be stiff, or increase muscle tone, goes to the spinal cord via nerves from the muscle itself. These nerves tell the spinal cord just how much tone the muscle has, and they are called sensory nerve fibers. The command to be flexible, or reduce muscle tone, comes to the spinal cord from nerves in the brain. These two commands must be well coordinated in the spinal cord for muscles to work smoothly and easily while maintaining strength.

In a child with cerebral palsy, damage to the brain usually has occurred. For reasons that are still unclear, the brain damage that occurs in these newborns tends to be in the area of the brain that controls muscle tone and movement of the arms and legs. The brain of the child with cerebral palsy is therefore unable to influence the amount of flexibility a muscle should have. The command from the muscle itself dominates the spinal cord and, as a result, the muscle is too stiff, or spastic.

Currently, it's impossible to operate on nerves in the brain and correct the brain damage, but it is possible to operate on the sensory nerve fibers that come from the muscle. During rhizotomy, each nerve root is divided into three to four nerve rootlets. By cutting some — but not all — of these rootlets, it is possible to reduce the message from the muscle to better balance the messages of flexibility (from the brain) with messages of stiffness (from the muscle). (See Figures 1 and 2 on next page.) Once the muscle tone becomes more normal, it's easier for the child to move and gain motor skills like sitting, crawling, standing and walking.

Remember that increased muscle tone or spasticity is only one problem of movement in children with cerebral palsy. Reducing spasticity will make it easier for the child to move but does not eliminate weakness, abnormal movements or balance problems.

## Benefits of Dorsal Rhizotomy

Dorsal rhizotomy reduces spasticity. The child will no longer feel so stiff; muscle tone will be more typical and movement will be easier. How much the child's mobility improves after surgery depends on several factors:

### THE DEVELOPMENTAL LEVEL OF THE CHILD BEFORE SURGERY

If the child was walking with a walker or crutches before surgery, these functions will likely be regained soon after surgery. Many children — but not all — will then progress to walk independently. A young child who was sitting alone and pulling up to stand (but not walking) prior to surgery has greater potential for walking with or without assistive devices after SDR.

### THE AMOUNT OF THERAPY THAT CAN BE PROVIDED AFTER SURGERY

Children change very rapidly after surgery. We recommend physical therapy four to five times a week for the first six months; three to four times per week for the next six months; and two to four times per week for the subsequent year or longer. We have found that this physical therapy schedule increases the possibility of your child reaching his or her maximum potential. Therapy is provided by your child's primary therapist, who is given a post-op physical therapy protocol to follow after surgery to best help your child. Physical therapists are invited to call us any time with questions. Intensive Therapy programs can be very beneficial for patients after selective dorsal rhizotomy; however we recommend waiting until patients are at least three to four months post-op.

### REDUCED SPASTICITY CAUSES BETTER MOVEMENT IN YOUR CHILD

Rhizotomy surgery reduces spasticity but does not have a direct effect on weakness, balance or abnormal movement patterns. These problems often improve because the child can move more easily after surgery, and strengthening is easier with reduced spasticity. These changes take time and persistence with physical therapy.

FIGURE 1

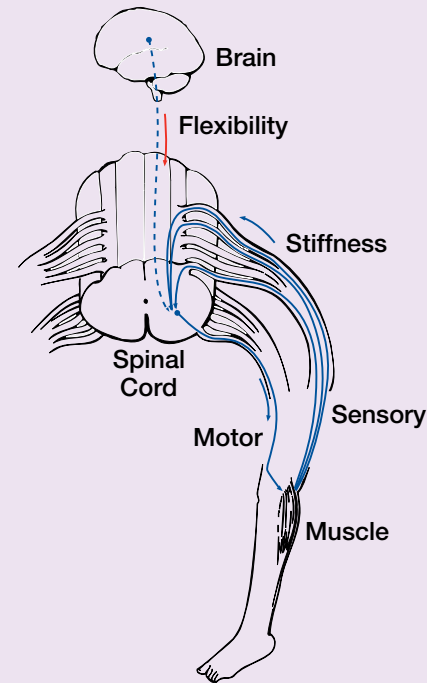
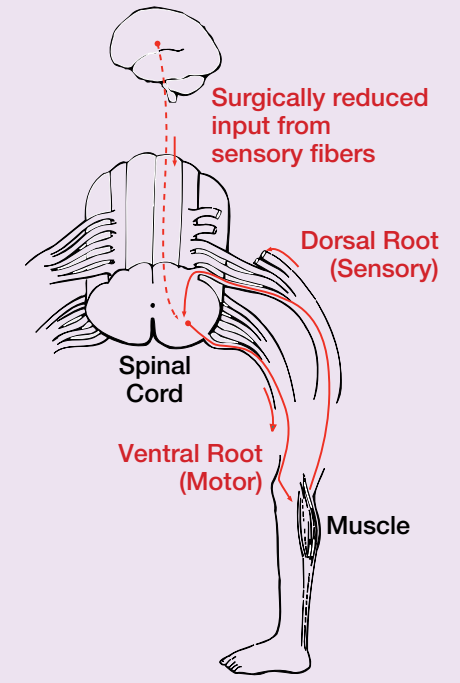


FIGURE 2



### THE CHILD'S MOTIVATION AND COOPERATION

These all play an important role in changing mobility. It is also important for the family to share the child's enthusiasm as new skills are gained, and to stay involved in the physical therapy program. The child needs opportunities to practice new skills at home, school and in the community.



## Could Your Child Benefit From Dorsal Rhizotomy?

Dr. Roland believes children with cerebral palsy spasticity should have an evaluation for potential dorsal rhizotomy before other orthopedic procedures are performed. All children with spastic diplegia, triplegia and quadriplegia following premature birth should be evaluated for the procedure.

### ESSENTIAL CRITERIA

- Diagnosis of spastic diplegia, spastic quadriplegia, spastic triplegia, spastic hemiplegia and simple hereditary spastic paraplegia
- Premature birth or full-term birth with typical signs of spastic diplegia
- 2 years of age or older
- No significant damage to the key area of the brain involved in posture and coordination, based on magnetic resonance imaging (MRI)
- At least three months since last Botox injection

### FACTORS TO BE CONSIDERED

- Adequate muscle strength in the legs and trunk. This is demonstrated by the ability to:
  - support full weight on the feet
  - hold a posture against gravity
  - make appropriate movements to crawl or walk
  - move quickly from one posture to another
- History of delayed motor development. The child can crawl, sit and pull to stand by age 2, but spasticity hampers the development of skills and/or causes gait deviations.
- Motivation and ability to cooperate in therapy.
- Commitment to rehabilitation and follow-up.
  - Receives physical therapy currently
  - Able to receive physical therapy four to five times per week for six months after the operation and with decreasing frequency for an additional one to two years
  - Ability to be followed by the St. Louis Children's Hospital rhizotomy team at four months post-op and regular intervals as needed
- If there is doubt that the child has adequate strength to change motor function, a three-month trial of physical therapy focused on strengthening may be recommended. Progress during this trial period will provide information about the child's potential to improve motor function after spasticity is reduced.
- History of orthopedic surgery. Previous orthopedic surgery does not mean your child is not a candidate for dorsal rhizotomy. However, we may recommend waiting at least one year following an orthopedic procedure to allow muscle strength to recover.

### ASSESSING YOUR CHILD'S CANDIDACY

If you are interested in being evaluated for the selective dorsal rhizotomy, please visit [stlouischildrens.org/SDR](http://stlouischildrens.org/SDR) and click on Patient Information Form to complete a screening. The last question on the form will ask how you prefer to be evaluated (by video or in-person). If your child meets the essential criteria, you will be emailed a set of instructions detailing all the information that needs to be collected to complete your packet.

If you are selected to come in for an appointment, we will schedule an appointment after our team has received your packet. If you select the video assessment, the rhizotomy team will review the videos produced by your home therapist, physical therapy evaluation, medical history, MRI and hip and spine X-rays to determine if your child is a candidate. You will then be contacted by the physical therapy coordinator to discuss the rhizotomy team's recommendations. There is no additional charge for the video assessment.

Children with cerebral palsy who possess certain conditions may not be candidates for the dorsal rhizotomy surgery. They include children who:

- have suffered meningitis, congenital infection, congenital hydrocephalus unrelated to premature birth, head trauma or familial disease
- have mixed cerebral palsy with rigidity, a predominance of dystonia or poor muscle tone
- have severe scoliosis
- will not make functional gains after surgery



## THE INITIAL EVALUATION

The initial evaluation consists of an appointment with Dr. Roland, a physician assistant and a physical therapist.

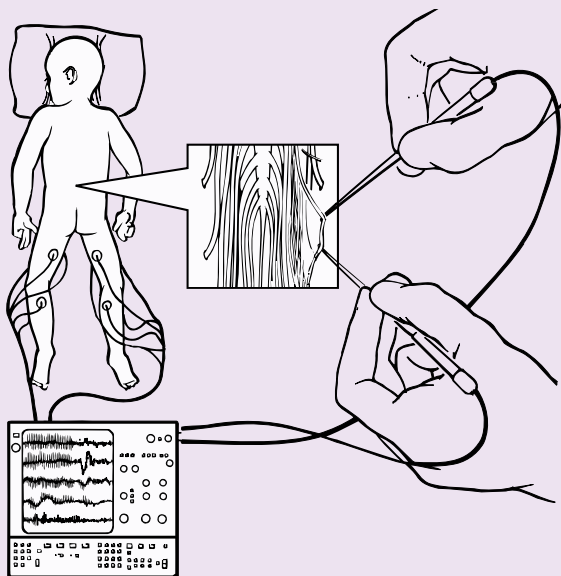
At the first appointment, a physical therapist will see your child to assess range of motion, wheelchair needs and discuss preoperative and postoperative physical therapy. Dr. Roland will examine your child and review his or her medical history along with the physical therapy evaluation. A physician assistant will be present during Dr. Roland's evaluation. Occasionally an MRI is requested after the initial appointment with Dr. Roland to better determine if your child is an appropriate candidate for the surgery. Please bring all assistive devices such as braces, a walker or crutches to your appointment.

## A Less Invasive Selective Dorsal Rhizotomy Procedure

Figure 3 on page 12 shows two groups of nerve roots that leave the spinal cord and lie in the spinal canal. The anterior nerve roots send information to the muscle; the dorsal nerve roots transmit sensation from the muscle to the spinal cord. At the time of your child's operation, the St. Louis Children's Hospital surgical team divides each of the dorsal roots into small rootlets and stimulates each rootlet electrically to identify the dorsal nerve rootlets that cause spasticity. The abnormal nerve rootlets are selectively cut, leaving the normal rootlets intact.

As Figure 3 illustrates, the surgery requires a 2-to-3-inch incision along the center of the lower back just above the waist. Dr. Roland is performing T.S. Park's procedure, which uses a smaller surgical site that often provides less pain and a faster recovery. In 1991, Dr. Park modified St. Louis Children's Hospital's surgical procedure to remove bone from one vertebrae instead of five or six. Once the surgery is complete, the skin is closed with glue; no stitches are required. The surgery takes about 3 hours while total operating time is around 4.5 hours. This accounts for going to sleep with anesthesia, positioning, setup, then waking up. Your child will go to the recovery room for a few hours before being transferred to the neurology/neurosurgery floor.

**FIGURE 3**



**The advantages of our minimally invasive laminectomy selective dorsal rhizotomy over other techniques include:**

- reduced risk of spinal deformities because less bone is removed
- less weakness after surgery
- less intense and shorter-term pain
- less recovery time needed and usually an earlier return to physical therapy

If your child develops a fever, respiratory symptoms or other medical problems within the month prior to the scheduled surgery, contact us at 314-454-2813. If your child is taking oral baclofen or gabapentin, he or she will need to be weaned off the medication at least two weeks before surgery. During the two weeks before surgery, your child should not take any pain or fever medication other than plain acetaminophen.

**FRAMING THE FUTURE**

On the day before surgery, our staff will video your child as he or she goes through a standardized test called Gross Motor Function Measure to determine the level of gait and functional skills. We will also assess range of motion and muscle tone. This video will be compared with progress after surgery videotaped at four-month and 16-month follow-up visits. Your child will also see a physician assistant the day before surgery for a history and physical examination.

**POSSIBLE SURGICAL ISSUES**

The dorsal rhizotomy is a long and extensive neurosurgical procedure for a child at any age. There are some risks associated with both the general anesthesia and the surgery, though, overall, the risks are minimal.

Dr. Roland will discuss the risks with you before surgery and answer any of your questions. Parents should also be aware that depending on existing conditions, some children may require additional orthopedic surgery following dorsal rhizotomy.

Dr. Roland collaborates with pediatric orthopedic surgeons who specialize in minimally invasive surgery to perform a surgical procedure for tendon and muscle lengthening to relieve joint contractures. Joint contractures are limitations in your child's joint movement.

The most common tendons that need to be lengthened are the hamstring and/or heel cords. The lengthening is done in the operating room through small incisions. Casting may be required, and patients can expect to spend one night in the hospital. Most patients begin physical therapy the day after surgery. Postoperative bracing is used for standing and advancing with walking. The size of the brace decreases over time as the patient gets stronger.

## Preparing for Surgery

The physical therapy program before surgery prepares you and your child for the physical therapy after surgery. Your child will learn what to expect immediately upon returning to therapy after surgery.

Physical therapy before surgery should focus specifically on the following areas:

- Strengthening the trunk muscles and the hips, knees and calve muscles
- Improving range of motion in the hip abductor, hamstring and gastrocnemius muscles
- Instructing the family in the preoperative and postoperative home exercise program
- Arranging for adaptive equipment to be used after surgery

## INSURANCE COVERAGE

Commercial insurance is a complex issue with any hospitalization and surgery. Generally, most insurance companies provide benefits for the selective dorsal rhizotomy. It is extremely important for you to contact your insurance company to notify them of the planned surgery. Be sure to obtain their written commitment to provide benefits. If you call your insurance company, you will need two code numbers: The diagnosis code (I-CD10) is G80.9. The procedure code (CPT) is 63190. Families should also check their physical therapy benefits using the CPT codes 97161, 97162, 97163 and 97110.

If your insurance company requires additional information, contact the rhizotomy administrative coordinator at 314-454-2813. Another helpful resource is the St. Louis Children's Hospital financial counseling staff members, who work closely with parents and are experienced in working with numerous forms of reimbursement. For financial counseling, call 314-454-6081.

## After Surgery

When your child is transported from the recovery room to the neurology/neurosurgery floor, he or she will have a catheter in the bladder and an intravenous line. The catheter will be removed on post-op day three.

After waking from the anesthesia, most children can move their legs but possibly not as well as before the operation. The legs will be less stiff than before surgery.

Your child will receive medications through an epidural catheter and intravenous line to relieve pain and reduce muscle spasms. Your child's face may appear swollen due to positioning during surgery, but this swelling will disappear in 24 to 48 hours. By the second or third day, your child will begin feeling better and will begin taking fluids by mouth. He or she will be positioned on their back or in a side-lying posture and will be turned from side to side every four to six hours.

Your child will be on bed rest until the third day after surgery, so you may want to think of activities your child can enjoy in bed. Some suggestions include a tablet and markers for drawing and coloring.

Many of these items are also available from the hospital's Child Life Services, located on the eighth floor.

Occasionally, children experience a headache after surgery. This can be medicated with an appropriate dose of acetaminophen.



## PHYSICAL THERAPY IN THE HOSPITAL

Your child will be limited to strict bed rest until the third day after surgery. On that day, your child will be assisted into a wheelchair for a maximum of one hour; support to keep the trunk straight is essential. A physical therapist will begin gentle therapy at this time. When your child is discharged, we will give you a copy of the preoperative physical therapy report and a postoperative physical therapy protocol to give to the primary physical therapist.

## BACK CARE AFTER SURGERY

There are no stitches to be removed from the skin. Some activity is allowed based on what your child can tolerate. The main restrictions are related to trunk movement. Your child is allowed to sit as tolerated; however, it is best to change position frequently during long periods of sitting, such as when traveling. If you have questions or concerns about your child's back, contact our office at 314-454-2813.



## Heading Home: The Future in Motion

When it is time to go home, you and your child may be feeling both excited and a little uncertain of what is to come. The first few weeks of recovery may be tiring for everyone involved. However, hope is on the horizon and many smiles await you.

### STRENGTH DEVELOPMENT

Your child will tire easily for the first few weeks at home. The muscle weakness that was hidden by the spasticity is unmasked by the rhizotomy, and strength development will take time. In addition, because of bed rest and limited activity for several days, it will take a while for normal strength and activity to return. For these reasons, your child should not return to school for three to four weeks after surgery.

### COMFORTING YOUR CHILD

It is normal for your child to complain of discomfort in the lower back, particularly when lifted or changing position. The inpatient physical therapist will demonstrate the proper methods to transfer and lift your child. Your child also may complain of pain if the feet dangle while sitting. We recommend using a stool to support feet and eliminate discomfort.

### ACTIVITY AND PLAY

Most children quickly resume sitting, crawling and kneeling if these skills existed prior to surgery. However, even if your child walked before surgery, it may take several weeks to walk after surgery due to weakness and poor muscle control. Encourage your child to be active on the floor — crawling, sitting and playing. Consult with your physical therapist if your child begins to stand or walk before this has been introduced as part of the physical therapy program.



### SLEEP

Occasionally, muscle spasms may disturb your child's sleep. These can be relieved by using a muscle relaxant prescribed at the hospital. We strongly encourage parents to fill this prescription and a prescription for pain medication before leaving the hospital to prevent any unnecessary discomfort for your child.

### TOILET USE

Some children's toilet habits change temporarily. This may be due to normal swelling or healing around nerves that go to the bladder. Be patient. While this can be frustrating to both the child and parents, it does resolve.

### SENSORY CHANGES

Most children will have hypersensitivity on the bottom of their feet after surgery. The child may complain of tingling, itching or funny sensations. This can be alleviated by wearing socks and shoes. Standing is often more comfortable when ankle-foot orthotics are worn in addition to shoes.

Place your hands firmly on the child's feet when dressing or bathing. Do not touch lightly or move your hands lightly over the skin. Hypersensitivity usually resolves in the first few weeks.

### HOME PROGRAM

At least for the first few months after surgery, your child's schedule will revolve around the physical therapy program. Home exercise programs are provided at discharge. Your therapist will give you specific activities and methods. Most of this program is learned during the preoperative and inpatient physical therapy. It is expected that families will perform a home exercise program in addition to the outpatient physical therapy.

### RECOVERY AND PROGRESS

Encourage your child to be active, but respect that he or she may tire easily. It takes time and repetition to produce consistent new movements. Some days your child will be frustrated because he or she has not yet learned new ways to control muscles and movements. Your child will not yet understand how to make the "new body" work. An image of a body without spasticity must be developed, and that takes time. The work is intense, but the rewards are tremendous.

Every child progresses at their own pace, and learning new skills is followed by a plateau while those skills are practiced. Other factors may cause setbacks. When your child goes through a growth spurt, there may be increased difficulties.

## OUTPATIENT PHYSICAL THERAPY

The St. Louis Children's Hospital rhizotomy team works to achieve an outpatient-based physical therapy program for patients who have undergone selective dorsal rhizotomy. The program includes an outpatient therapy protocol in coordination with the child's primary home therapist. Therapy Services has also developed an Intensive Therapy Program that consists of two hours of physical therapy and one hour of occupational therapy provided on a daily basis for one or two weeks. The goals for the physical therapy program are to:

- Increase strength in the trunk, hips and legs
- Develop alignment of pelvis, trunk and head
- Increase range of motion of the legs
- Develop isolated movements of the legs as well as opposing movements
- Improve balance
- Develop the ability to move in and out of position
- Develop and improve walking
- Incorporate new patterns of moving in and out of position for functional skills
- Increase endurance of functional activities such as walking or bicycle riding

## Follow-Up Appointments

### FOUR MONTHS POST-OPERATION

- The Children's Hospital treatment team will examine the child four months after discharge. This appointment is mandatory for families residing in the United States and families are expected to return for that appointment.
- If the family doesn't agree to or is unable to return for this post-op visit, the rhizotomy surgery will not be considered for the child.
- Prescriptions will be given for patients up to one year following the last appointment at the rhizotomy clinic.

### ONE YEAR AFTER FIRST POST-SURGERY VISIT

- At the four-month postoperative appointment, the family will discuss with Dr. Roland and the rhizotomy team if another appointment is needed one year later.
- If the family, Dr. Roland and the rhizotomy team agree that another visit in a year is not necessary, the patient and family will be counseled regarding follow-up by an orthopedist, rehabilitation physician, neurologist or another doctor.

- If the patient and family, or Dr. Roland and the rhizotomy team feel that another appointment in one year would benefit the child, a return appointment can be requested.
- During each of these appointments, the child and family will meet with Dr. Roland to discuss postoperative progress. This is also an opportunity for the child and family to ask questions regarding the type and frequency of PT, integration into community sports and activities, bracing needs and changes in assistive devices.

At the postoperative appointment, patients/families may be asked to bring new hip X-rays. During these appointments, the patient will see Dr. Roland for examination and will see a physical therapist for an evaluation, which will be recorded on video. After each clinic appointment, the medical records will be sent to the child's primary care physician and physical therapist.

Sending a video of the child's motor function is not considered an adequate examination of the child and will not take the place of either a postoperative or follow-up appointment at the rhizotomy clinic.

## Understanding Terms

### CONTRACTURE:

The shortening of a muscle, tendon or other structure so that the joint cannot be straightened or readily flexed and extended.

### DIPLEGIA:

Involvement primarily in the hips and legs; trunk and arms may be involved to a lesser degree.

### MRI:

Magnetic Resonance Imaging uses the body's natural magnetism to produce a clear picture of the structure being scanned.

### NEUROSURGERY:

Surgery involving the brain, spinal cord or nerves.

### QUADRIPLEGIA:

Equal involvement of all four arms and legs.

### SPASTICITY:

Stiffness in the muscles of the arms, legs and trunk.



## Our Team Addresses Your Concerns

### **COULD THERE BE A REOCCURRENCE OF SPASTICITY AFTER SURGERY?**

There has been no return of spasticity in children with spastic diplegia, a form of cerebral palsy. A small portion of children with spastic quadriplegia have had return of spasticity.

### **DO CONTRACTURES GO AWAY WITH SURGERY?**

Contractures are the shortening of muscles, tendons and other structures so they cannot be straightened or easily flexed and extended. The underlying cause of contracture is removed by the surgery, so contractures may be improved. However, if the contracture is severe and does not respond to a stretching/positioning program, serial casting or orthopedic surgery may be necessary.

Serial casting involves a series of casts, applied at weekly intervals, to increase muscle length using a slow gentle stretch over a long period of time — usually three weeks. If a child has significant contractures at 5 years or older, orthopedic surgery may be necessary, especially if other conservative treatments have failed. Minimally invasive orthopedic surgery can be performed in two to six months after rhizotomy.

### **HOW LONG HAVE YOU BEEN DOING DORSAL RHIZOTOMY SURGERY?**

The team at St. Louis Children's Hospital began performing the surgery in 1987 and have performed the surgery on more than 5,300 patients ranging in age from 2 to 50 years.

### **WILL THE SURGERY ENABLE MY CHILD TO WALK?**

Selective dorsal rhizotomy can improve walking to varying degrees, but some children do not make significant improvement for various reasons. Problems with abnormal muscle coordination, weakness and abnormal reflexes may continue to be evident. But better range of motion, better sitting postures and improvements in gait patterns can be expected.

### **WILL THE SURGERY ENABLE MY CHILD TO WALK?**

Selective dorsal rhizotomy can improve walking to varying degrees. Some children do not make significant improvement for different reasons. Problems with abnormal muscle coordination, weakness and abnormal reflexes may continue. Better range of motion, sitting postures and gait patterns can be expected.

### **WHAT IMPROVEMENTS COULD MY CHILD HAVE IN SPEECH?**

Some children's speech improves, but this is not predictable. An improvement in the child's trunk position may be a factor. Having more support, when sitting, can allow for better breathing and ability to make sounds.

### **ARE THERE IMPROVEMENTS IN MY CHILD'S UPPER BODY FUNCTION?**

Some progress is evident. This appears to be related to the improvement of trunk control and pelvic position.

### **WILL MY CHILD NEED ORTHOTICS OR SPLINTS?**

Most children require an orthotic for the foot and ankle after surgery to maintain proper alignment of the foot during weight-bearing activities. Often, existing orthotics can be modified after surgery. If your child needs new orthotics around the time of surgery, we recommend they be fitted after surgery.

## For More Information

For more information about selective dorsal rhizotomy surgery, you or your physical therapist may call the St. Louis Children's Hospital Center for Cerebral Palsy Spasticity at **314-454-2813**.

Additional information is also available at [stlouischildrens.org/SDR](http://stlouischildrens.org/SDR), or join our group on Facebook.

# Notes

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## St. Louis Children's Hospital

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[StLouisChildrens.org/SDR](https://www.stlouischildrens.org/SDR)



St. Louis Children's Hospital and Washington University Physicians comply with applicable federal civil rights laws and do not discriminate on the basis of race, color, national origin, age, disability or sex.

Atención: hay servicios de asistencia de idiomas disponibles a su disposición sin costo.

Llame al 314-747-5682 (TTY: 1-800-735-2966).

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