

Parent Guide to Selective Dorsal Rhizotomy

Your child's doctors believe your child is a good candidate for selective dorsal rhizotomy, also known as SDR.

SDR is a standard neurosurgical operation used to treat spasticity—a condition in which certain muscles are stiff and tight—in the legs. Specialists working with Kennedy Krieger Institute have a great deal of experience in performing the surgery. Should you and your family decide to proceed with the surgery, your child will be in good hands.

It's important for you and your family to be prepared for both the surgery and the rehabilitation period that follows it. After surgery, your child will need to do intensive physical therapy for a minimum of six months and up to a year to increase strength, develop balance and alignment, and eventually increase independence at home and at school. Other therapies may be needed as well.

Our approach to SDR surgery is supported by scientific studies. Research has found that children with leg spasticity

who undergo the procedure and follow it with physical therapy experience a significantly greater improvement in gross motor abilities than children with leg spasticity who undergo physical therapy alone.

Before your child's surgery, you will receive guidance from your Kennedy Krieger care team on arranging for ongoing, appropriate outpatient physical therapy after your child has been discharged from our hospital. The team will also anticipate your child's post-surgical orthotic needs, and will initiate acquiring new orthotics for your child if indicated.

The information in this guide will help you understand what to expect during and immediately following the surgery, as well as during the first year after the surgery. It will also help you prepare for the surgery itself.

About the Surgery

SDR surgery is typically appropriate for children 3 to 12 years old who have both bilateral spastic cerebral palsy and the ability or potential to walk. Surgery lasts three to four hours and is performed in an operating room at The Johns Hopkins Hospital, which is adjacent to Kennedy Krieger. Your child will be asleep under general anesthesia during the surgery.

Your child's neurosurgeon will make a small incision in your child's lower back, and—using special equipment—will locate the abnormal nerve rootlets in your child's spine and cut some or all of them, leaving normally firing rootlets intact.

Pre-Surgery Preparation

Medication management

When scheduling your child's surgery, we will review the medications he or she is currently taking. Before surgery, your child might need to gradually stop taking certain medications. Our team will work with you to manage any medication changes.





Stress management

Before (as well as after) your child's surgery, our experienced child life specialists—who are trained in child development, education and psychology—will be available to help you, your child and other family members minimize the stresses associated with surgery and hospitalization. Most importantly, they will help your child, in an age-appropriate manner, better understand what is happening. When young people understand what is happening to them and why, they can cope more effectively and respond better to medical treatment.

Following Surgery

Inpatient Recovery

Immediately following surgery, your child will stay as an inpatient at Johns Hopkins for about five days. During that time, any pain your child experiences will be carefully managed, and your child's position in bed will be carefully monitored.

At Johns Hopkins, your child will be seen by a physical therapist, who will help your child with his or her first post-operative walks. These walks will help your child stay healthy and recover from the surgery itself. You may be allowed to walk with your child during this time. The focus of these walks will be on getting up and moving.

Inpatient Rehabilitation

When your child is ready to begin rehabilitation, he or she will be transferred to Kennedy Krieger's inpatient rehabilitation hospital for four to eight weeks of post-surgical rehabilitation and therapy. At Kennedy Krieger, walking to recover from surgery will be replaced with learning how to walk correctly. This may take some time.

During inpatient rehabilitation, your child will begin the intensive work needed to learn how to control his or her muscles and movements in order to maximize the results of the surgery. Your child will have a very full and individualized schedule, which will include physical and occupational therapy sessions, child life activities, therapeutic recreation, "school" time with a teacher or education specialist, behavioral psychology appointments, and other sessions and activities, as appropriate.

Physical therapy during inpatient rehabilitation will focus on helping your child relearn ways of moving that he or she could not perform well when spasticity was in the way. This will include:

- Performing exercises to strengthen underused muscles
- Learning how to use these muscles in new ways for improved gross motor skills
- Improving balance and coordination

Since the therapy will involve learning new things, your child will work on more basic skills at first, progressing to walking when he or she is ready. If a child progresses to walking too quickly, he or she risks using muscles in old and ineffective ways. Your child will have specific positioning routines to practice, some of which will require using a mobile stander. Your child's therapist will help him or her progress to walking with new and improved patterns during the inpatient rehabilitation stay.

Because we are so concerned about your child's quality of walking, walking outside of therapies will initially be limited. Once your child is walking correctly at a certain level of consistency, a therapist will clear him or her to walk with you and your child's other trained caregivers.

After discharge, your child may still need to use an assistive walking device—a walker, for example—until his or her strength and muscle control are developed enough to permit independent walking. Sometimes a wheelchair may be

needed for longer distances. Your child's care team may also recommend new braces. Always remember: We are here to make your child's transition home from the hospital as smooth as possible.

In addition to helping your child learn how to walk correctly, your child's inpatient rehabilitation team will help your child improve his or her mastery of basic activities of daily living, such as dressing and bathing. And your child's team will work to ensure your child will be ready to return to school. Your child may continue to do schoolwork during hospitalization, and we will work with your child's school to ensure a smooth transition back to class.



Following Inpatient Rehabilitation

After leaving our inpatient rehabilitation hospital, your child will still require physical therapy. For at least the first six months, appointments will need to take place four to five days a week so your child can continue strengthening his or her muscles and learning how to control new movement strategies. Over time, appointments can decrease to three times a week, as your child continues to progress during that first post-operative year.

Your child may receive outpatient physical therapy through Kennedy Krieger's outpatient programs, or from a physical therapist in your home community or your child's school. Ideally, your child's outpatient therapy provider will be chosen before surgery. Your Kennedy Krieger care team will be available to help you locate and evaluate therapy services in your community. You'll want to check with your health insurance provider to be sure services at specific locations are covered under your plan.

Whether your child receives outpatient therapy at Kennedy Krieger or at a therapy provider in your home community, your child's inpatient therapy team will discuss plans for therapy with the outpatient therapist.

After the first six months of outpatient therapy, physical therapy will continue for the rest of the first year after surgery, at a frequency of one to three times a week. At this stage of recovery, physical therapy is frequently paired with a physical activity, such as ballet or martial arts, to ensure daily skilled activity. Changes resulting from the SDR surgery may initially be subtle, and may not be fully realized for one to two years.



Return to School and Activities

Once your child has been discharged from inpatient rehabilitation services, he or she will be ready to return to school. Before discharge, your child's inpatient care team will provide you with guidance and recommendations for your child's return to school and extracurricular activities. If your child's status has changed due to surgery, our education specialists will assist with any accommodations the school would need to make. Your child's neurosurgeon will clear your child to participate in certain activities, such as bike riding and swimming, when appropriate.

Interdisciplinary Spasticity Management Program Follow-Up

Your child will follow up with the Interdisciplinary Spasticity Management Program Clinic three to four months after inpatient rehabilitation discharge, in order to monitor progress and provide an ongoing plan of care recommendations. After that initial clinic follow-up appointment, you and your child will return to the clinic at six months, twelve months and two years after the surgery.



Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Kennedy Krieger Institute provides care that preserves cultural, psychosocial, spiritual and personal values, beliefs and preferences. Care is free from discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression, including transgender. We encourage patients and families to become active partners in their care by asking questions, seeking resources and advocating for the services and support they need. © 2018 Kennedy Krieger Institute 8/2018

Notes

Contact Information

For more information, please contact the Kennedy Krieger Institute Interdisciplinary Spasticity Management Program Team at:

Phone: **443-923-9440**

Fax: **443-923-9445**

Email: **SDRInfo@KennedyKrieger.org**

To make an appointment, call **443-923-2600**. For urgent concerns outside of office hours, call **443-923-9200**.

Forms

All forms for school, nursing care, medical equipment, etc. may be sent to us at the fax number above, or to:

Rehabilitation Department
Attention: Fred Finkenbinder
707 North Broadway
Baltimore, MD 21205

Team Members

Clinical coordinator: **443-923-9440**

Pediatric nurse practitioner: **443-923-7995**

Orthopedic surgeons: **443-923-2700** and
443-997-2663

Physiatrist: **443-923-9440**

Neurosurgeon: **443-923-7995**

Physical therapist: **443-923-9280**

Inpatient case manager: **443-923-9416**

Outpatient nurse coordinator: **443-923-9440**