

Reflex Neurovascular Dystrophy Treatment Services for Children and Adolescents at The Children's Institute

When a child is suffering from chronic pain that seems to last longer or be more intense than would be expected, the problem may be a condition known as reflex neurovascular dystrophy (RND). Other names for this condition include amplified musculoskeletal pain of childhood, reflex sympathetic dystrophy (RSD), pediatric fibromyalgia and complex regional pain syndrome (CRPS).

What We Know about RND

The pain associated with these conditions may be in one or more areas of the body and may also travel through the body. It may be so intense that even a breeze can be excruciating to the affected area. This constant pain may cause children to miss significant amounts of school and to discontinue participation in activities.

Because the source of pain in RND is unknown and cannot be pinpointed during medical examinations, children are often mistakenly told that they are imagining the pain or are incorrectly diagnosed with severe mood disorders. But the pain is real and can make daily activities frustrating for those children suffering from the condition. Fortunately, help is available.

What to Expect at The Children's Institute

The RND Program at The Children's Institute is based on RND treatment developed by David Sherry, MD¹, and includes intense exercise therapy to the area(s) affected by the pain syndrome. This treatment breaks the cycle of pain and desensitizes the nerves. It promotes increased strength, endurance, agility, and function as well as reduces hypersensitivity.

Patients also receive psychological therapy that consists of a cognitive-behavioral approach to pain management. We have found that instruction in stress management to be an important aspect of pain management, regardless of the cause of the pain, since pain is a stressor and often there may be a relationship between stress and the increase in pain or in RND flares. Education about the mind/body connection, identification of one's stressors, the recognition of stress symptoms, relaxation training, and problem-solving strategies is our primary focus.

Inpatient RND treatment at The Children's Institute typically ranges from two to four weeks based on the patient's individual needs. Patients have a daily schedule of three to five hours of physical and occupational therapy. Treatment also includes stress reduction, relaxation techniques and psychological counseling. All sessions are mandatory unless the patient has a high-grade fever. Patients perform their therapy independent of their family so that they can focus on their therapists' instructions. All patients are discharged with

a home exercise program (HEP), which is built from exercises and activities a patient learns while in treatment at The Children's Institute and is begun during the inpatient stay. A patient's continuation of their HEP after discharge is a key element in long term management of RND.

Full participation is necessary for RND programming to be successful. Therefore, our expectation is that each patient will attend all scheduled therapies daily and complete HEP nightly.

Occasionally, a child or adolescent in the inpatient program may feel unable to follow the prescribed treatment recommendations. Because full participation is considered to be mandatory for continued inpatient stay, the treatment team will take a stepwise approach to resolve any obstacles to the child or adolescent may be experiencing.

Initially, members of the treatment team will encourage the child to remain in programming with positive reinforcement. The individual will be given the opportunity to make up for missed therapy time at the end of the day or, if more than one hour is missed, continue on the following day.

If a child or adolescent does not appear to be physically or emotionally ready to complete the inpatient program, as evidenced by consistent refusal of therapy sessions or the HEP, the recommendation will be made for discharge. An early discharge will be handled in a manner that will be appropriately supportive. In the event of an early discharge, the team will focus on the patient's accomplishments and make efforts to encourage the likelihood of patient's participation in treatment at a future time.

¹ Dr. Sherry developed the treatment program in Seattle, Washington, where it continues today. Currently, he leads a similar program at Children's Hospital of Philadelphia.