

The Very Real Pain of RND

Childhood is a time for playing, learning and the occasional scrape, bruise and growing pain. But for some children, day-to-day activities become limited because of intense, unrelenting pain. Pain so severe that getting out of bed is a challenge and physical activities are nothing more than a memory. These children are suffering from reflex neurovascular dystrophy (RND).



A rowing machine is part of the daily therapy for RND patient Marissa Cozza, 13.

What Is RND?

RND is regarded as a pain amplification syndrome and is in the same family as fibromyalgia, reflex sympathetic dystrophy, chronic regional pain (types I and II) and causalgia. RND affects the nerves leading to the blood vessels. The nerves become overactive, causing a very real, intense pain that can be debilitating. Limbs are usually affected, but the condition can cause pain anywhere.

The exact causes of RND have yet to be determined, but injury, illness and especially stress seem to be factors. Age, genetics and hormones may also contribute.

According to Robin Barbara, MEd, licensed psychologist, The Children's Institute (CI), the typical RND patient is a high-achieving, compliant, young adolescent girl who may internalize her experiences of daily stress.

"The demands and expectations placed on kids are much greater today than in the past, and RND patients may not be able to recognize this as stress," explains Robin. "But they're only able to manage for so long before what seems like one small incident is the straw that breaks the camel's back. RND is one of the many ways the body has of reacting to stress."

Since there are no tests for RND, diagnosing a child with the condition can be difficult.

"Kids with RND can be in pain for months or even years before they're diagnosed," says Jamie Calabrese, MD, medical director, The Children's Institute. "Families go from doctor to doctor with either no diagnosis or an incorrect diagnosis."

"The symptoms can be so severe and intense that concerns over a possible autoimmune disease or malignancy arise," explains Paul Rosen, MD, clinical director, Division of Rheumatology, Children's Hospital of Pittsburgh and consulting physician for CI's RND program. "Families can become distraught when the pain persists without a diagnosis and treatment plan."

The RND Program at The Children's Institute

When Dr. Calabrese joined The Children's Institute as medical director two years ago, implementing a chronic pain program was high on her list of goals for



Alexandra (Ali) Rice, 15, manages her RND one step at a time with the help of Adina Dildine, Physical Therapy.

the organization. She and a team of CI therapists traveled to Children's Hospital of Philadelphia to study the Pain Management Program of David Sherry, MD, a leader in RND diagnosis and treatment.

Today, CI is one of only a few places in the United States, and the only in the area, to house a comprehensive, inpatient pain management program dedicated to treating RND.

"We treat the whole child," says Dr. Calabrese. "From physical and occupational therapists to psychologists, we have a fantastic team who is committed to healing these kids."

CI's program depends on physicians such as Dr. Rosen who have a special interest in joint pain to diagnose patients with RND and refer them for treatment. Once referred, children undergo an evaluation and are informed about the rigorous rehabilitation program. The children, with the help of their families, decide whether or not they want to join the program.

"We tell the kids immediately that we know their pain is real, that we can help," says Janey Farber, Physical Therapy, The Children's Institute. "But it's an incredibly intense program, so they need to decide for themselves whether or not they can commit completely."



The RND program includes intensive, inpatient treatment for two weeks. When children enter the program, physicians discontinue all medications, and patients begin their road to recovery with therapy sessions that last five to six hours each day. All sessions are mandatory unless the patient has a high-grade fever, and the children perform their therapy independent of the family so that they can focus on the therapist's instruction.

"By the middle of the first week of therapy, the kids are starting to feel different," says Janey. "The pain is not gone, but they can walk without a limp or put their own shirt on again."

Through extensive physical therapy to the areas affected by the pain syndrome and psychological therapy that focuses on the connection between the mind and body, the cycle of pain is broken, and nerves to the blood vessels are retrained. As a result, the patient experiences an increase in strength, endurance and agility, as well as a decrease in hypersensitivity to pain.

Although the pain may not be eliminated by the time patients are discharged, it's usually significantly less than what it was originally. With continued home exercise sessions, psychological follow up and stress management therapy, the pain will eventually cease to exist. Follow-up visits to the referring physician and CI help ensure progress and proper management of RND.

"These kids are empowered by knowing that working through their exercises, no matter how painful they may be, will eventually make them feel better," says Janey.

New Beginnings

The recovery rate for RND is largely unknown, although anecdotal data suggest that children and adolescents have a better chance for recovery than adults with similar pain syndromes. Noted RND specialist Dr. Sherry has published reports documenting that 92 percent of children reach full function at the end of two weeks of treatment, and 88 percent are pain-free after five years. Because there are no controlled studies under way, the success rates are based on physician observation.

What is known is that children with RND are more likely to develop other stress-related conditions, including pain syndromes, eating disorders and depression. Follow-up therapies, from physical to psychological, are critical to keeping the condition under control. In the process, patients learn that by taking control of their body and doing their exercises, they can control their pain.

"It's all about putting kids in the driver's seat when it comes to their bodies," says Dr. Calabrese. "Through the program, we provide them with the necessary tools and offer them the support they need for continued success."

If you're interested in learning more about the RND rehabilitation services at The Children's Institute, please call 412-420-2113 or visit www.amazingkids.org.

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