International Center for Spinal Cord Injury at Kennedy Krieger Institute







After you've experienced a spinal cord injury, life as you know it changes forever. But recovery is possible, potentially even years after injury.

Conventional wisdom used to hold that the bulk of recovery from a spinal cord injury occurred in the first six months after the injury, and that improvement was virtually impossible after two years. "Rehabilitation" focused mostly on teaching patients how to compensate for injuries and conditions thought to be irreversible. But that conventional wisdom is now outdated.



At Kennedy Krieger Institute's International Center for Spinal Cord Injury, children and adults with chronic paralysis find new hope through activity-based restorative therapy. Let us help you regain some sensation, functioning, mobility and independence, months—or even years—after your diagnosis. Our doctors, social workers, psychologists, physical therapists, occupational therapists and spinal cord specialists work together as a team to help you reach your maximum potential. Every person and every spinal cord injury and dysfunction are different. Our goal is to help you achieve the best therapeutic result and outcome possible for you.

"I've just learned how strong a person I am. People have been telling me that I could do anything if I put my mind to it. Every little step that I make is a big step for me; I just look at it as one more thing that's going to help me get out of the chair. Now I can move my left leg a little. That's going to make me strive even harder to get out of the chair."

Our Treatment Approach

At the International Center for Spinal Cord Injury, doctors and physical and occupational therapists use innovative rehabilitation approaches to help individuals with paralysis gain improved health and quality of life. Many of our patients recover some degree of sensation, movement and independence. Depending on your injury and rate of progress, you may do several hours of therapy a day, two to five days per week.

Activity-Based Restorative Therapy

If you have a spinal cord injury, the connection between your brain and the part of your body below your level of injury has been damaged or lost. Your brain cannot tell that part of your body to move. Activity-based restorative therapy (ABRT) helps patients with spinal cord injuries perform activities using specially designed exercise equipment that prompts the nervous system to "remember" how to move.



The goal of ABRT is to increase mobility by activating the nervous system above and below the level of your injury, encouraging your brain and nervous system to form new connections, even after many years with paralysis. These therapies can also help you avoid common complications of paralysis such as osteoporosis, skin breakdown, infection, cardiovascular decline and other signs of premature aging, which are costly to treat and detrimental to your overall quality of life.

ABRT at the center includes a variety of therapeutic activities, including functional electrical stimulation; repetitive, intensive practice of functional activities; blood-flow restriction therapy; weight-bearing activities; locomotor training; and gait training.

Functional Electrical Stimulation

In functional electrical stimulation (FES), a computer sends electrical messages to your muscle, causing it to contract in a way that can be used for purposeful movement, such as grasping an object or riding an FES bike. Cycling for one hour is equivalent to walking 6,000 steps. FES is often used in combination with other therapies.

Aquatic Therapy

Water can support about 90 percent of a person's weight and provides a unique therapeutic environment. People with paralysis can perform activities in water that



would be impossible for them to do on land. Aquatic activities like walking on an underwater treadmill can provide the patterned stimulation needed to promote optimal activation of the nervous system.

Partial Weight-Supported Walking Therapy

In partial weight-supported walking (PWSW) therapy, you are suspended in a harness, which allows you to walk over an electric treadmill at a very low speed. If you are not able to start stepping on your own, two therapists will help you move your legs to ensure an efficient and technically correct gait. Gait training allows you to relearn natural walking while recovering mobility. You'll bear progressively more weight as gait patterns are reestablished. If you have an incomplete spinal cord injury, PWSW is followed or complemented by traditional over-ground walking.

Strengthening and Practicing Activities

You will also spend therapy time working on strengthening the core muscles of your trunk and abdomen, which you use to sit and stand. In addition, we will spend time on standing activities to prepare for more patterned activities that simulate walking. Our therapy center is equipped with state-of-the-art rehabilitative equipment that is often incorporated into these therapy activities. Depending on your individual goals, therapy will also include practicing specific tasks that will promote your recovery and help you meet your goals. For example, some patients may practice grasping things with their hands to help them achieve independence in dressing themselves, while others may work on improving the strength of their grip so they may complete transfers more safely.



Who Can Benefit

When many people think of spinal cord injuries, they often think of sudden, traumatic injuries, such as falls or injuries from automobile accidents. But paralysis can also be caused by conditions such as transverse myelitis, acute flaccid myelitis, multiple sclerosis, spinal tumors and arteriovenous malformations. The programs offered at the International Center for Spinal Cord Injury can benefit individuals with paralysis caused by any of these conditions.

In addition, people with other rare neurological disorders—such as neurofibromatosis, adrenoleukodystrophy, vascular malformations of the central nervous system, ALS (amyotrophic lateral sclerosis, or Lou Gehrig's disease) and Friedrich's ataxia—are also well-suited to these programs.

At the center, we welcome children, adolescents and adults to our medical and therapy programs. Our center is one of the first in the world focused on rehabilitation and restoration for children with paralysis. While most traditional therapy programs are designed for adults and must be modified for children, we have programs and equipment that have been developed specifically for children and adolescents. Additionally, the members of our interdisciplinary team have years of experience developing and tailoring treatment plans with the unique physical, developmental, educational and social needs of children in mind. Our therapists combine recreational and functional activities to both motivate children and improve their skills. Since our center treats both children and adults, we can provide children with a seamless transition from pediatric to adult care, ensuring children will continue to receive the care they need into adulthood.

Chronic Spinal Cord Injury

Although the International Center for Spinal Cord Injury welcomes patients in the acute phases of rehabilitation, the center focuses on long-term therapy programs that you can continue at home. Over time, these techniques are significantly less costly and easier to adapt to your individual or family's lifestyle than inpatient rehabilitation.

The center's ultimate goal is to help you recover mobility and independence, but the therapies pursued here can also benefit those who do not recover neurologic function. People with paralysis often face skin breakdowns, infections, osteoporosis and other symptoms of premature aging resulting from immobility. Our approach promotes movement to help you avoid complications caused by immobility that can threaten quality of life and are costly to treat.

"I don't know where we'd be without Kennedy Krieger. They've basically taught us everything we know how to do. They're part of the family. We really wouldn't be anywhere without them."

– Caryn, mother of Caetlyn







Our Programs

Treatment plans are developed in consultation with you and your family, and are tailored to meet your unique needs. A board-certified spinal cord injury medicine physician or pediatric rehabilitation nurse practitioner, along with a therapy team, evaluate your medical history and conduct a thorough physical examination before the first therapeutic session. The results are used to adapt therapy to your individual capabilities and goals, and regular reevaluations occur throughout the process to ensure continued safety and effectiveness.

Inpatient Program for Children, Teens and Young Adults

Our inpatient program, directed by a physician, welcomes patients from birth to age 21 and treats acute and chronic spinal cord dysfunction in children, including those who need ventilator assistance. Based on our initial evaluations of your child, we design an intensive rehabilitation and treatment program that is tailored to the unique needs of your child and family. While in our inpatient hospital, your child will receive at least four hours of therapy each day, plus opportunities for child life and therapeutic recreation.

Outpatient Programs for Children and Adults

Our outpatient programs welcome patients of all ages and include a medical clinic, a therapy program, an aquatic therapy program and a variety of additional services. The medical clinic focuses on physical health and quality of life, and provides specialized outpatient evaluations, periodic follow-up and medical management. In our outpatient therapy program, our expert team delivers intensive evaluation and ABRT treatment. If appropriate, your therapy program may include both traditional, land-based ABRT and aquatic therapy. Therapy sessions are conducted on an individual basis and focus on the achievement of goals established by you and your physician and therapist. Upon discharge, you will receive an individualized, detailed home rehabilitation program to follow to maintain and improve upon gains between bouts of therapy.

There are three options for outpatient therapy:

Short-term intensive therapy: In this five-days-a-week program, patients attend therapy for two to three weeks and receive a minimum of three hours of therapy each day. This program is convenient for patients who do not live within commuting distance of Kennedy Krieger.

Extended intensive therapy: In this program, patients attend therapy one to three times per week for eight to 12 weeks and receive a minimum of three hours of therapy per session. This program is convenient for patients who live near Kennedy Krieger.

Telehealth appointments: Telehealth appointments allow us to treat patients who are unable to be at our center for health and safety reasons. Using secure teleconferencing technology allows us to provide specialized medical and therapy services to patients who require them.

Aquatic Therapy Program

Designed to complement land therapy, aquatic therapy is used as a treatment modality throughout the rehabilitation process and offers many benefits to patients with varying levels of functioning. The center has two state-of-the-art pools with a range of warm water temperatures and therapeutic treatment options, built-in treadmills for retraining and observing gait patterns, video systems for monitoring therapy activities, multiple jets for resistance training, and floors that operate on lifts to allow for barrier-free entry and exit, ensuring easy access by patients who use wheelchairs for mobility.





Other Services

Social work and psychology services: Adjusting to paralysis or a spinal cord injury is a lifelong process. We help you come to terms with your diagnosis and learn about your injury. Our center's social worker and psychologist support you in building a life that is not just focused on your disability. Instead, you will learn how to integrate yourself back into your community and live a meaningful, purposeful life.

Seating Clinic: Selecting the appropriate wheelchair and seating system is important, especially if you depend on a wheelchair for mobility. This clinic helps with that process by providing comprehensive evaluations, recommendations and fittings of wheelchairs and specialized seating systems.

Orthotics Clinic: We provide an interdisciplinary approach to bracing through comprehensive examinations, assessments and analysis to make recommendations that will best meet your needs and optimize your functioning through appropriate bracing.

Dry needling: This skilled intervention stimulates trigger points, muscles and connective tissue to help manage pain and lessen movement impairments.

Life Through Motion Wellness Program: As part of our continuum of care, our wellness program includes gym access, group fitness classes, independent aquatics, personal training and nutrition services. Being active outside of therapy helps you build and improve strength, flexibility, balance, endurance and cardiovascular health. **Wound care and healing:** We offer an interdisciplinary approach to wound healing and services to improve your health, wellness and participation in the community by promoting both skin healing and the prevention of skin breakdown. In addition, our therapists are certified to treat and evaluate lymphedema.

Adaptive and Rehabilitative Sports Program: Our commitment to lifelong health extends beyond the hospital walls. Adaptive sports and recreational activities can be important tools in improving your health and quality of life by rebuilding strength, increasing independence, building self-confidence and just having fun with others. We offer a range of programs, including adaptive handcycling, virtual and adaptive sailing, adaptive fishing and surfing, and wheelchair lacrosse. Through these activities, you can achieve goals you might have thought would be impossible. Visit **KennedyKrieger.org/Adaptive-Sports** to learn more about the program.

Peer Mentoring Program: Partnering with the Christopher and Dana Reeve Foundation, this program connects you with supportive peer mentors who understand what it's like to live with paralysis or care for someone with paralysis.

Regeneration Generation: This monthly patient education group is open to anyone with paralysis, as well as to their caregivers and family members. Each month's meeting features a new topic and exciting speakers.



Additional services:

- Bone density measurements by dual-energy X-ray absorptiometry (DXA) scans to prevent, detect and treat osteoporosis
- Urodynamic studies to assess and address bladder performance (available only to adult patients)
- Nurse consultation regarding skin issues and bowel and bladder management
- Ongoing monitoring by our nursing staff
- Nurse case management for information and general assistance



PATIENT SUCCESS STORY

Marcel's Story

Marcel is such a happy little boy. "He's gregarious. He loves music, and he's just a fun kid," says his mom, Naimah.

But that wasn't the case the day Marcel, who has Down syndrome, developed transverse myelitis (TM). He didn't want to walk, and when Naimah picked him up, his legs just fell underneath him. "Right away, I knew something was not right," she says. Within hours, Marcel, then 2, was paralyzed from the waist down.

Marcel came to Kennedy Krieger as an inpatient, and then transitioned to outpatient care at the Institute. The interdisciplinary care he's received through the International Center for Spinal Cord Injury has included physical, occupational and aquatic therapies, which have helped him not just cope with the paralysis caused by TM, but recover from it.

"We are really focused on recovery," explains Brooke Meyer, one of the center's senior physical therapists. "We're not trying to compensate for the paralysis; we're truly trying to activate and restore the nervous system, so we can facilitate as much recovery as possible.





On Marcel's first day of physical therapy, three physical therapists helped Marcel into a child-size harness over a treadmill. One moved Marcel's right leg, another moved his left leg, and a third held Marcel's hips up. "For the first time in six months," Naimah says, "I saw my child on his feet, walking again."

Marcel has made incredible progress. He can now sit up on his own, scoot around on the floor and use his arms to play without worrying about falling over, and he's standing and walking with assistance.

At Kennedy Krieger, "they give us hope through seeing our kids in motion again," Naimah says. "It's just amazing."

Visit KennedyKrieger.org/Marcel to watch Marcel's story.

Our Team

Because patients recovering from spinal cord injury or paralysis may have complex needs, an experienced, interdisciplinary treatment team works with each patient.

The team includes:

- Adaptive aquatic specialists
- Aquatic therapists
- Assistive technology professionals
- Child life specialists
- Nurse case managers
- Nurse practitioners
- Nurses
- Occupational therapists

• Physiatrists

Orthotists

• Personal trainers

- Physical therapists
- Psychologists
- Seating and mobility specialists
- Social workers

Research Initiatives

Every day, our patients show us that ABRT improves day-to-day and neurologic function, overall health, and quality of life. At the International Center for Spinal Cord Injury, we are constantly assessing our therapeutic interventions' effectiveness, continuing to develop new and improved technologies, and testing new clinical interventions, in order to improve patient care and advance the field of spinal cord rehabilitation and restoration.

Visit **SpinalCordRecovery.org** to learn more about current research efforts, publications and clinical trials.



"I could finally feel comfortable and know that my daughter was in the best care. They [the staff at Kennedy Krieger] were very informative, very gracious, very understanding, kind. They truly love what they do and it shows."

- Eric, father of Sanayah



Contact Information

For the convenience of its patients, the International Center for Spinal Cord Injury has two locations in the Baltimore-Washington, D.C., region. For more information or to schedule an appointment at the location that best serves you, please call **443-923-9222**, or call toll-free at **888-923-9222**. TTY users, please contact us at **443-923-2645**, or dial **711** to make a Maryland Relay call.

Referral specialists are available Monday – Friday, 8:30 a.m. – 5 p.m.

Mailing Address 707 North Broadway Baltimore, MD 21205

Visit SpinalCordRecovery.org to learn more.

Our Mission

At Kennedy Krieger Institute's International Center for Spinal Cord Injury, we dedicate ourselves to helping children and young adults with disorders of the brain, spinal cord and musculoskeletal system achieve their potential and participate as fully as possible in family, school and community life.

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. © 2020 Kennedy Krieger Institute 06/2020

