

COMPREHENSIVE CEREBRAL PALSY AND MOVEMENT DISORDERS PROGRAM

Enhancing movement, empowering lives

CookChildren's





Did you know? ● ● ● ●

- *There is a wide variety of movement disorders, ranging from mild to severe. Some movement disorders get progressively worse over time.*
- *Cerebral palsy is the most common disabling movement disorder in children, affecting three out of every thousand children.*
- *Most dystonia starts in childhood or adolescence. Early recognition and aggressive intervention is the key to improving function and limiting disability over time.*

Our treatment philosophy: enhancing movement, empowering lives

At Cook Children's, we know it's about more than medical expertise and advanced technology. It's about working together to tackle even the most complex condition.

That is why the Cook Children's Comprehensive Cerebral Palsy and Movement Disorders program offers a full range of diagnostic and therapeutic interventions based on a patient-centered, interdisciplinary team approach. Our movement disorders and neuromuscular clinics have dedicated teams of professionals, including physicians, nurse practitioners, physician assistants, physical therapists, occupational therapists, speech therapists, orthotics and prosthetics technicians, a clinical nurse specialist, a patient liaison, a social worker, bio-behavioral therapists, Child Life specialists and therapy dogs. The team works to meet the specific needs of each individual child and family, by developing comprehensive treatment plans that will enhance movement and empower lives.

Cook Children's Comprehensive Cerebral Palsy and Movement Disorders program serves approximately 2,900 children each year and offers:

- One of the largest motion analysis laboratory dedicated to children in the United States.
- One of the most experienced with pediatric deep brain stimulation in the United States.
- One of the most experienced in using the intraoperative-MRI image-guided lead placement system, that helps reduce the need for secondary epilepsy surgeries.
- Two decades of experience in spasticity management using botulinum toxin and intrathecal baclofen pumps.
- Selective dorsal rhizotomy (SDR) surgery as an option for some patients with spasticity.
- A full range of electrophysiologic testing.
- A comprehensive Tourette syndrome treatment program.
- Both inpatient and outpatient rehabilitation programs.

Cook Children's is a Muscular Dystrophy Association-sponsored neuromuscular clinic and is active in clinical research to enhance the lives of people affected by movement disorders.



The **intraoperative MRI** has improved the accuracy of our lead placement for deep brain stimulation in patients with dystonia.

Our **advanced motion analysis laboratory** plays a critical role in our treatment planning and outcome assessments.

Deep brain stimulation, approved by the FDA (with a humanitarian device exemption) since 2003, has offered relief to many patients with dystonia.

OUR TECHNOLOGY

Deep brain stimulation (DBS): leading-edge treatment

In 2007, Cook Children's became the first children's hospital in the United States to offer a dedicated pediatric deep brain stimulation program. Since then, more than 100 children with primary and secondary dystonias have benefited from DBS at Cook Children's. Since the inception of our DBS program, our team has been actively involved in sharing our experience. We have made presentations at national and international meetings and have hosted visiting physicians and teams for interactive learning. In 2016, in collaboration with international partners, we became founding members of PEDiDBS, the international data-sharing registry for pediatric patients undergoing DBS. Many of our patients travel long distances for our DBS expertise, and we are prepared to assist. We work with local physicians to ensure a smooth plan of care.

What is DBS?

DBS involves sending minute electrical signals to specific areas of the brain to control abnormal movements. The primary brain target for pediatric dystonia is the globus pallidus internus. The system has three implanted components: the intracranial lead with four separate contacts is placed into the desired target. An **extension** lead connects the lead to the **implanted pulse generator (IPG)**. The **IPG** is programmed to deliver the desired impulses using a small external computer placed over the IPG. Programming can be changed as often as needed.

iMRI has revolutionized DBS surgery

Before the introduction of our intraoperative MRI, children undergoing DBS surgery were lightly sedated, yet awake, during the placement of the electrodes into their brain. This was necessary to allow microelectrode recordings to aid in lead placement. With the iMRI, leads are placed visually in fully sedated children. Patients are usually discharged one day after lead placement. The incidence of lead placement revisions has been greatly decreased with the use of the iMRI.

Our advanced motion lab, that opened in June 2015 helps us understand the consequences of movement disorders. The motion lab uses fully integrated biomechanical hardware and software, including 14 infrared cameras and 12 force plates and 16 channel wireless electromyography (EMG). A plantar pressure evaluation system allows static and dynamic evaluation of pressure points of the feet. A wireless oxygen consumption study is used to analyze energy efficiency. We have incorporated a UL Certified over-ground harness system with dynamic body weight support to allow evaluation of partially ambulatory patients and for gait training. It helps promote faster recovery, reduce the length of stay and minimize risk to both patients and clinicians.





We have added a movement-based system providing rehabilitation exercises with audio-visual stimuli. This virtual reality system helps the physical therapist evaluate the patient's progress and modify the rehab program as needed.

Our team works actively with the technology vendor to enhance the quality of studies delivered. We performed more than 100 studies in our first year. The motion analysis studies have helped tailor our treatment plans for complex patients. Five patients were recommended for selective dorsal rhizotomy (SDR) and two for DBS, in addition to multiple complex orthopedic surgeries. Walk-aid evaluations also are done in our motion analysis lab and we're collaborating on other uses for the lab to improve children's lives.

Intrathecal spasticity and pain management using intrathecal baclofen (ITB) was first offered at Cook Children's in 1997. Since then, more than 275 patients have benefited from ITB. We collaborate with our pain management program to offer intrathecal pumps for relief of refractory pain.

Chemodenervation, using botulinum toxin and phenol, provides temporary relief from pain or abnormal postures from spasticity or dystonia. Our physicians have performed thousands of chemodenervation procedures. These can be done in the office or under general anesthesia in dedicated procedure rooms under the guidance of board certified pediatric anesthesiologists.

MOVEMENT DISORDERS SERVICES

In the **Complex Motor Disorders Clinic**, our neurologists partner with rehabilitation therapists, orthotists and a social worker dedicated to the evaluation and follow-up of patients.

Cook Children's Neuromuscular Clinic has a longstanding relationship with the Muscular Dystrophy Association (MDA). In addition to our MDA-sponsored neuromuscular clinic, our team supports the annual summer camp for children with neuromuscular disorders.

Rehabilitation Services is a vital part of caring for children with cerebral palsy and other movement disorders. We offer both inpatient and outpatient rehabilitation services. Our inpatient neuro-rehabilitation unit uses the same family-oriented, patient-centered treatment philosophy to help children recover to their maximum potential after illness or injury.

Therapy goals are developed based on the needs of each child to encourage ongoing recovery. When patients are admitted to the **rehabilitation care unit (RCU)**, they receive an individualized treatment plan with goals focused on home, school and community re-entry. An on-site teacher from Fort Worth Independent School District (FWISD) assists with daily school activities to make it easier for the children and teens to return to school. Parents and caregivers actively participate in setting goals for the child's return home and learn how to care for him/her each step of the way.

Cook Children's RCU features:

- 16 private rooms
- Parent bed space in each room
- State-of-the-art gym for therapies
- Overhead lift track for activities of daily living and therapies
- FWISD classroom
- Family-centered play area
- Wireless internet so you can stay connected with your family, school or work

Comprehensive behavioral intervention for tics (CBIT) is an integral part of our Tourette syndrome management program. This dynamic interactive therapy performed by certified bio-behavioral therapists teaches patients how to regain control of their bodies rather than being ruled by disruptive movements. With aggressive use of CBIT, the need for medications can be reduced and in many patients eliminated.





Selective dorsal rhizotomy (SDR) is a surgery performed on the spinal cord in the low back of children with cerebral palsy or spasticity in the legs. There are two kinds of nerve rootlets in the spine – dorsal rootlets and ventral rootlets. The dorsal roots are ones that carry signals from the child’s legs to the spinal cord and then to the brain. These are the roots that usually have abnormal communication between the muscle and the brain, therefore allowing spasticity in the muscle. In the surgery, very specific dorsal rootlets are cut to reduce the spasticity while preserving the child’s ability to move.

Most candidates are able to walk, with or without the use of an assistive device, and have relatively good leg strength and muscle control. However, there are some cases in which we perform surgery in non-ambulatory children, in order to improve their care. Ultimate candidacy is determined by our team of doctors and clinicians, but is usually performed on children between the ages of 2-10 years who have a diagnosis of cerebral palsy causing increased spasticity, or stiffness, in their legs.

Motion analysis is done in our state-of-the-art motion lab using a 3-D, computer-assisted system. It involves merging data from muscles, joints and ground reaction forces to provide a comprehensive model of the actions involved in a movement. Information on foot plantar pressures and energy expenditure complete the picture, giving the clinician an accurate assessment of the movement in question, and offering a guide to therapeutic interventions. Most commonly used to assess gait problems in cerebral palsy, the same principles can be applied to any normal or abnormal movement.

PEDiDBS

In 2016, in collaboration with international partners, we became founding participants in **PEDiDBS**, the international data-sharing registry for pediatric patients undergoing DBS. PEDiDBS is open to any center worldwide performing DBS on patients up to age 22 years. Information can be found at pedidbs.org.





CEREBRAL PALSY AND MOVEMENT DISORDERS PROGRAM

EXPERIENCE COUNTS: BY THE NUMBERS

Cerebral/spasticity clinic –
patients served annually – **600**

Movement Disorders program
(excluding tics) – patients served
annually – **1,000**

Botox procedures – patients
served annually – **900**

Deep brain stimulation (DBS)
neurostimulators – total
patients served – **110**

Implanted baclofen pumps – total
patients served – **300**

Selective dorsal rhizotomy (SDR) – total
patients served – **6***

**Began SDR in January 2016*

OUR TEAM

Our team is made up of physicians, nurse practitioners and physician assistants in the following specialties:

- Neurology
- Neurosurgery
- Orthopedics
- Pain Management
- Clinical Genetics
- Metabolic Genetics
- Pulmonology
- Cardiology
- Palliative Care

Rehabilitation therapy includes:

- Physical therapists
- Occupational therapists
- Speech therapists
- Orthotics and prosthetics technicians

Support staff includes:

- Clinical nurse specialist
- Patient liaison
- Social worker
- Child Life specialists and therapy dogs
- Bio-behavioral therapists

CEREBRAL PALSY AND MOVEMENT DISORDERS PROGRAM PHYSICIANS:

Neurology

Warren Marks, M.D.

Medical Director, Rehabilitation and Movement Disorders

Medical Director, Motion Analysis Lab

Cerebral Palsy

Movement Disorders

Neuromuscular Disorders and EMG

Fernando Acosta Jr., M.D.

Cerebral Palsy

Movement Disorders

Stroke

Stephanie Acord, M.D.

Cerebral Palsy

Movement Disorders

Tourette Syndrome

Neurosurgery

John Honeycutt, M.D.

Medical Director, Neurosurgery

Co-director Jane and John Justin

Neurosciences Center

Functional and Stereotactic Neurosurgery

Deep Brain Stimulation

Baclofen Pumps

Richard Roberts, M.D.

Neurosurgery of the Spine and Peripheral Nerves

Selective Dorsal Rhizotomy

Baclofen Pumps

Brachial Plexus and

Peripheral Nerve Repair

David Donohue, M.D.

Baclofen Pumps

Daniel Hansen, M.D.

Baclofen Pumps

Orthopedic Surgery

David Gray, M.D.

Medical Director

Scoliosis and Spine Surgery

Developmental Orthopedics

Ronald Burke, M.D.

Scoliosis and Spine Surgery

General Orthopedics

Jason Kennedy, M.D.

Developmental Orthopedics

Lauren Lamont, M.D.

Developmental Orthopedics

Matthew Mayfield, M.D.

Developmental Orthopedics

John Roaten, M.D.

Developmental Orthopedics

Pam Sherman, M.D.

Hand Surgery

Pain Management

Artee Gandhi, M.D.

Medical Director

Traditional and Complementary Medicine

Meredith Brooks, M.D.

Traditional and Complementary Medicine



Jane and John Justin Neurosciences Center at Cook Children's includes:

Neuropsychology • Neurodiagnostic-registered EEG technologists • Social workers • Neurosurgeons
Patient liaison • Speech therapists • Case managers • Child Life specialists • Pediatric nurse practitioners
Epileptologists • Neuroradiologists • Neuropharmacists

FOR REFERRALS, contact:

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International referrals:

www.cookchildrensinternational.org

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