# Philip A. Keelty Center for Spina Bifida and Related Conditions at Kennedy Krieger Institute

## Who We Are

The Philip A. Keelty Center for Spina Bifida and Related Conditions serves children and adults with spina bifida, myelomeningocele (meningomyelocele) and myelodysplasia, as well as other related conditions of the brain and spine, such as hydrocephalus, Arnold-Chiari malformation and tethered spinal cord syndrome. We also see children with other complex birth defects, such as caudal regression syndrome, sacral dysgenesis and other multiple congenital anomaly syndromes. Through an interdisciplinary approach, we provide quality medical care that focuses on optimizing health and functioning, preventing secondary conditions and coordinating healthcare services.

## **Our Team**

Individuals with spina bifida and spinal cord defects have complex medical and rehabilitation issues involving multiple systems, particularly affecting the central nervous, urinary, gastrointestinal and musculoskeletal systems. The Keelty Center team brings together specialists from multiple disciplines to provide comprehensive medical care, including:

- Physical medicine and rehabilitation (physiatry)
- Physical therapy
- Occupational therapy
- Neuropsychology
- Social work
- Nutrition
- Pediatric orthopedics

## Our Approach

Spina bifida is a complex condition that requires comprehensive care to address multiple challenges. The Keelty Center offers a unique approach to comprehensive spina bifida care by integrating care and support not only for a patient's medical needs, but also for habilitative, educational and social issues, such as school readiness or athletic participation.

We also evaluate and treat secondary conditions—such as weakness, learning disabilities, chronic wounds, and bowel and bladder incontinence—through a working partnership between Kennedy Krieger team members and our patients and their families. Treatment plans are coordinated with the patient's family, primary care provider, school and other applicable community services.



# **Clinical Services**

Our interdisciplinary team works closely with our patients and their family members to develop a treatment plan that meets the individual needs of each patient. Physical and occupational therapists help patients maximize mobility and functioning for increased independence.

Medical and rehabilitative interventions include:

- Adaptive sports and recreation
- Aquatic therapy
- Assistive technology
- Bracing and casting
- Feeding and nutrition
- Neuroimaging
- Neurosurgical procedures and care

- Occupational therapy
- Orthopedic care
- Orthotics
- Physical therapy
- Recreational therapy
- Seating evaluations
- Social work evaluations



#### **Prenatal Consults**

In our prenatal consults, parents will have the opportunity to meet with members of our spina bifida team, which may include a pediatric physical medicine and rehabilitation doctor, a neuropsychologist, a social worker and a nurse. During the visit, our team will talk about what our clinic offers to support individuals with spina bifida. While each person is different, we can provide information to families based on our experience following children and adults with spina bifida throughout their lives, as well as research and best practice recommendations.

#### Infants Clinic

Closely monitoring a child's development from all perspectives is particularly important in the child's first year. Our Infants Clinic team includes a pediatric physical medicine and rehabilitation doctor, a social worker and a neuropsychologist. We also work closely with local Infants and Toddlers Programs to monitor our patients' gross and fine motor and speech development.

#### **Collaborative Management**

At each clinic visit, our team routinely monitors patients for any developmental issues or complications that may require further studies or procedures. We make sure all needs are met through direct collaboration with our surgical partners.

#### **Orthopedic Surgery**

Orthopedic surgical interventions vary depending on the degree of impairment and the potential for functional improvement. Our orthopedic experts combine operative care with intensive postoperative physical and occupational therapy to maximize surgical outcomes and rehabilitation benefits.

Some of the most common procedures include:

- Clubfoot repair
- Spinal surgery for scoliosis
- Hip reconstructive surgery
- Hip dislocation surgery
- Surgical release of contracted muscles and tendons

#### Neurosurgery

Under the direction and expertise of Johns Hopkins neurosurgeons, we offer a variety of neurosurgical interventions to aid in the management of spina bifida and other spinal cord deformities.

These neurosurgical procedures include:

- Hydrocephalus management with shunt placement or revision
- Tethered cord evaluation and management
- Fetal closure surgery performed before birth—typically between 19 and 26 weeks of pregnancy

#### Urology

Urologic oversight is essential for management of neurogenic bladder and prevention of kidney and bladder injury.

Some of the most common approaches to determining and treating urologic conditions include:

- Kidney and bladder ultrasounds
- Urodynamic studies, including the evaluation of sphincter-bladder coordination and bladder pressure

### **Contact Information**

#### Philip A. Keelty Center for Spina Bifida and Related Conditions at Kennedy Krieger Institute

For more information or to schedule an appointment, please call **443-923-9400**, or call tollfree at **888-554-2080**. TTY users, please contact us at **443-923-2645**, or dial **711** to make a Maryland Relay call.

#### KennedyKrieger.org

**Physicians and Healthcare Professionals** To make a referral, call our Physician Referral Line at **443-923-9403**.

#### **Clinic Location**

Kennedy Krieger Institute 801 North Broadway Baltimore, MD 21205

#### Mailing Address

Kennedy Krieger Institute 707 North Broadway Baltimore, MD 21205

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