

Adult Spina Bifida Clinic

at Kennedy Krieger Institute

Who We Are

The Adult Spina Bifida Clinic, a part of the Philip A. Keelty Center for Spina Bifida and Related Conditions, provides comprehensive, evidence-based interdisciplinary care for adults living with spina bifida and related diagnoses, including:

- Myelomeningocele
- Lipomeningocele
- Sacral agenesis
- Tethered cord syndrome
- Hydrocephalus
- Syringomyelia

As the only center in Maryland and the surrounding states dedicated to adult spina bifida care, our clinic provides lifelong, coordinated support addressing the unique and evolving medical, surgical and psychosocial needs of adults living with spina bifida.

What We Offer

Our interdisciplinary and innovative care for adults is centered around routine monitoring to develop an individualized treatment plan for each patient. This routine care includes:

Neurological monitoring: We provide routine monitoring for symptomatic tethered spinal cord and shunt malfunction, and we partner with neurosurgical experts in shunt and tethered cord surgical needs.

Neurogenic bowel and continence management: We are passionate about helping people reach their goals for bowel management and social continence, and we understand the impact this has on quality of life. Services include medication management, transanal irrigation training (including with the Peristeen® and Navina® systems), and antegrade flush management for cecostomies (e.g., Chait Trapdoor® cecostomy tubes and button devices) and appendicostomies (a.k.a. Malone antegrade colonic enema [MACE]).

Urological care: We monitor kidney and bladder health and functioning through routine screenings, perform urodynamics studies when appropriate, and assist with attaining and maintaining social continence, including catheter training. Our urology partners provide



essential oversight, as well as pharmacological and surgical interventions, to optimize management of neurogenic bladders.

Occupational therapy: Our specialists provide oversight of rehabilitation needs, with a focus on maximizing independence, strength and mobility.

Dedicated social work support: Patients work with a spina bifida specialist who provides counseling and evaluation for necessary resources.

Neuropsychological testing: Coordinated neurocognitive evaluations to identify cognitive strengths and weaknesses are available to inform strategies for independent functioning, learning and accommodations.

On-site laboratory and imaging services: Our on-site services include phlebotomy, DEXA scans (monitoring for osteoporosis), urodynamics testing and X-rays, as appropriate.

Seating services: Seating experts fit patients for wheelchairs and other assistive equipment, as needed, to improve mobility.

Our Team

The adult spina bifida clinic functions as a medical home for spina bifida-related care, working in partnership with primary care providers to deliver comprehensive management, preventive health services and care coordination. The interdisciplinary team includes medical, rehabilitation and mental health specialists who ensure coordinated management of neurological, musculoskeletal, urologic, gastrointestinal and psychosocial needs throughout the lifespan.

Our on-site providers include:

Care coordinators: Three nurse coordinators, two medical assistants, and a spina bifida clinic coordinator comprise our Care Coordination Team. Together, they ensure seamless communication, appointment scheduling and care coordination across all services.

Physiatrists: A physiatrist is a clinician who specializes in physical medicine and rehabilitation (PM&R). Our physiatrists provide comprehensive medical expertise to optimize functioning, mobility, independence and overall quality of life for adults with spina bifida.

Neurogenic bowel nurse practitioner: This nurse practitioner specializes in the assessment and management of bowel dysfunction related to spina bifida, with a focus on social continence.

Occupational therapist: Our occupational therapist evaluates patients' fine motor skills and equipment needs and coordinates with Kennedy Krieger's Seating Clinic for customized seating solutions.

Social worker: Our social worker offers mental health counseling and evaluates resource needs and barriers to care for adults with spina bifida.

Neuropsychologist: This clinician provides specialized cognitive and psychological assessment and support for transition-age youth and adults with spina bifida.

Orthotist: An orthotist from Momentum O&P (formerly C.D. Denison), a non-Kennedy Krieger clinic specializing in orthotics and prosthetics, provides customized bracing evaluation and fitting to support mobility and functioning.

Partner specialists: We maintain established relationships with the neurosurgeons, urologists and orthopedics providers who see our adult patients at Johns Hopkins Medicine, and we collaborate closely with them to ensure our patients have well-rounded care.

Our Approach

In accordance with Spina Bifida Association guidelines, our clinic's approach to care for individuals with spina bifida is tailored to age and specific needs and includes routine health promotion, preventive screenings and anticipatory guidance. We offer individualized counseling on topics such as mobility, neurogenic bowel and bladder management, skin care, nutrition, and adaptive equipment, as well as support for transition to adult care, transition to higher education and/or the work force, and community integration.

We emphasize patient education, proactive monitoring for complications, and ongoing support for self-management and independence, and we provide resources to optimize health outcomes and quality of life. Our clinic is committed to delivering patient-centered, lifelong interdisciplinary care for all individuals with spina bifida, regardless of age and life stage.

CONTACT US

Adult Spina Bifida Clinic at Kennedy Krieger Institute

For more information or to schedule an appointment, please call **443-923-9440** or **443-923-9130**. TTY users, please contact us at **443-923-2645**, or dial **711** to make a Maryland Relay call.

KennedyKrieger.org

Clinic Location
801 North Broadway
Baltimore, MD 21205

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