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Editorial Comment: LUTD in rare pediatric neurological conditions: A joint report by the neurourology promotion committee and children and young adults committee

The joint report by the Neurourology Promotion Committee and the Children and Young Adults Committee of the International Continence Society (ICS) provides a comprehensive overview of neurogenic lower urinary tract dysfunction (NLUTD) in rare pediatric neurological disorders. This initiative deserves high recognition not only for its scientific merit but also for its clinical relevance. By systematically categorizing uncommon conditions into complex anatomical, genetic, neurodevelopmental, metabolic, and malignant groups, the authors have broadened the clinician's perspective beyond the well-known entities such as spina bifida and cerebral palsy.

One of the major contributions of this report lies in its integrated understanding of neuroanatomy and function. The authors skillfully explain how lesions at different levels—from suprapontine to peripheral nerves—can disrupt the coordination of storage and voiding. The inclusion of disorders such as VACTERL association, caudal regression syndrome, and urofacial (Ochoa) syndrome underlines how both structural and developmental factors may lead NLUTD. Equally valuable is the recognition that behavioral and neurodevelopmental disorders such as ADHD and autism spectrum disorder (ASD) may also be associated with bladder dysfunction. In these children, the underlying mechanisms are multifactorial, involving complex interactions between sensory processing abnormalities, heightened anxiety, communication difficulties, behavioral dysregulation, and motor coordination challenges. Recognizing these multifactorial contributors is essential for developing individualized, behaviorally management strategies and for avoiding unnecessary invasive investigations.

This review will certainly serve as a valuable guide in the management of children with rare neurogenic bladder disorders; however, future versions could be further expanded to include neuroinflammatory and autoimmune diseases that can also cause lower urinary tract dysfunction, such as acute disseminated encephalomyelitis, pediatric multiple sclerosis, transverse myelitis, and Guillain–Barré syndrome [1–4].

A crucial point emerging from this body of evidence is that there are currently no standardized follow-up protocols for these children. The heterogeneity of underlying syndromes and the diversity of neurological involvement make uniform guidelines difficult to establish. Therefore, follow-up should be individualized according to disease severity, renal risk, and cognitive or behavioral profile. In this context, clinicians are encouraged to prioritize non-invasive monitoring tools—such as bladder diaries, uroflowmetry, ultrasound assessment of post-void residual urine, and renal imaging—for routine surveillance. Invasive urodynamic studies should be reserved for specific indications, such as evidence of upper tract deterioration, recurrent infections, or refractory incontinence, where the results are likely to alter management. This balanced, stepwise approach aligns with the ethical imperative of minimizing procedural burden in children with complex neurological and developmental disorders, while still safeguarding renal function and continence.

Another underappreciated aspect is that NLUTD in these populations is not merely a urological problem but part of a broader multisystemic phenotype. Renal protection, infection prevention, bowel management, and psychosocial well-being must all be addressed within a multidisciplinary framework that includes neurologists, nephrologists, rehabilitation physician, and psychiatrists. The report rightly calls for early identification and coordinated care, which are essential for improving long-term outcomes and quality of life.

In conclusion, this ICS report is a significant step forward in organizing and contextualizing the fragmented knowledge surrounding rare pediatric neurological diseases and their urological sequelae. Yet, the clinical spectrum is even broader than currently presented. The next frontier will be to establish individualized, evidence-based, and minimally invasive monitoring strategies that respect the unique vulnerabilities of each syndrome. By doing so, pediatric urologists can ensure not only the preservation of renal function but also the dignity and quality of life of children living with rare neurological disorders.

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