Media Release

Thai Society for Pediatric Endocrinology and DKSH Raise Awareness of Rare Genetic Bone Disorder XLH

The Thai Society for Pediatric Endocrinology, DKSH, the Thai Rare Disease Foundation, and the XLH Community collaborate to raise awareness of the rare genetic bone disorder X-linked hypophosphatemia, aiming to improve patient outcomes and quality of life in Thailand. The initiative highlights progress in genetic testing and treatment options, promotes multidisciplinary care models, and encourages parents to recognize early signs of the disease to maximize the potential for effective treatment and recovery.

Bangkok, Thailand, February 19, 2026 – The Thai Society for Pediatric Endocrinology, DKSH Business Unit Healthcare, the Thai Rare Disease Foundation and the XLH Community join to raise awareness of X-linked hypophosphatemia (XLH), a rare genetic bone disorder caused by low level of phosphate that can lead to skeletal deformities, impaired growth, and chronic pain. The initiative underscores the importance of early diagnosis and timely treatment. It also highlights advancements in diagnostic testing and treatment options, offering renewed hope to patients and their families.

Healthcare professionals, patient representatives, caregivers, and industry partners recently gathered in Bangkok during “XLH Day” to share updates on clinical advances and multidisciplinary care models, with an aim to improve outcomes for people living with the rare disease. Medical experts reported steady progress in the diagnosis, treatment, and long-term care of patients with XLH in Thailand. It was also emphasized to be vigilant for early warning signs to ensure timely intervention.

The Importance of Early Diagnosis of XLH
XLH is a rare inherited bone disorder caused by mutations in the PHEX gene, leading to elevated levels of fibroblast growth factor 23 (FGF23) and chronic phosphate loss. The condition can result in bone deformities, impaired growth, chronic pain, and psychosocial challenges.

While XLH remains a rare condition and is difficult to diagnose, many patients receive a late diagnosis and develop bone disorders. Increasing awareness among parents, caregivers, and frontline healthcare professionals plays a key role in identifying symptoms early and initiating appropriate care to prevent irreversible complications and improve long-term quality of life.

Thailand Advances XLH Screening and Treatment
In Thailand, genetic testing capabilities have improved significantly. However, access and affordability remain ongoing challenges, underscoring the need for continued policy support. The diagnosis can only be carried out at tertiary and teaching hospitals, while the screening cost is high and cannot be reimbursed.

Today, pediatric endocrinologists are based nationwide, improving access to specialist care for patients and families outside major urban areas. In parallel, the Thai Society for Pediatric Endocrinology promotes multidisciplinary care and family support services to address the full spectrum of patient needs.

The therapies for XLH patients include Phosphate syrup, vitamin D tablets and an anti-FGF23 treatment. It is expected that by 2026, phosphate syrup will be replaced by phosphate tablets as it is difficult for children to maintain due to frequent dosing and poor palatability. Phosphate tablets are more convenient and require less frequent dosing. Moreover, two real-world patients shared during the event that they experienced meaningful improvements in quality of life, mobility, and bone density, following access to the anti-FGF23 treatments.

Addressing Challenges Through Policy and Collaboration
Medical experts and patient advocates highlighted the importance of continued policy action, including XLH registration, improvement on patient transfers and telemedicine models to reduce travel burdens for patients outside major cities. Additional priorities include expanding benefit coverage for genetic testing and breakthrough XLH therapies in order to support sustainable access to diagnostic testing and future treatments.

Voices from the XLH Community
Prof. Dr. Suttipong Wacharasindhu, President of the Thai Society for Pediatric Endocrinology, said, “Advancements in the diagnosis and treatment of XLH have transformed patient care, offering new hope and improved quality of life. We are dedicated to continuing this progress by expanding treatment options and ensuring broader and more equitable access to care.”

Naiyaphak Kunaviriyasiri, President of the Thai XLH Community, shared the lived experience of XLH, noting: “This disease affects patients both physically and mentally, as it can cause body deformities that lead to a loss of confidence. However, the disease is treatable. As a patient myself, I would encourage others with XLH to follow their doctors’ instructions and take their medication consistently. Most importantly, it is essential to maintain a positive mindset.”

Prof. Dr. Somjit Jarurattanasirikul, Vice President of the Thai Society for Pediatric Endocrinology, remarked: “Following this event, all participating parties have clear mandates. We anticipate significant progress in the coming years. Our goals are to establish clinical guidelines for XLH and to implement targeted therapy as the universal standard of care for all patients.”

As part of its ongoing commitment to underserved patient communities, DKSH continues to support efforts to expand access to treatment and medical innovation for rare diseases, including XLH. Furthermore, it promotes social understanding to support the long-term well-being and quality of life of rare disease patients.

About DKSH
For more than 160 years, DKSH has been delivering growth for companies in Asia Pacific, Europe, and North America across its Business Units Healthcare, Consumer Goods, Performance Materials, and Technology. As a leading Market Expansion Services provider, DKSH offers sourcing, market insights, marketing and sales, e-commerce, distribution and logistics as well as after-sales services, following its purpose of enriching people’s lives. DKSH is a participant of the United Nations Global Compact and adheres to its principles-based approach to responsible business. Listed on the SIX Swiss Exchange, DKSH operates in 35 markets with 26,840 specialists, generating net sales of CHF 11.1 billion in 2025. DKSH Business Unit Healthcare distributes pharmaceuticals, consumer health, over-the-counter products and medical devices. With around 7,580 specialists, the Business Unit generated net sales of CHF 5.8 billion in 2025. www.dksh.com/hec

For more information please contact:

DKSH Business Unit Healthcare
Kamonkarn Parwasuthikarn
Manager, Group Marketing & Communications, Healthcare
kamonkarn.p@dksh.com