International Comprehensive Consensus Issued on Management of Achondroplasia

Nemours Children's Health contributes to important guidelines that address the lifespan of people born with genetic disorder known for causing dwarfism.

Wilmington, Del. (December 14, 2021) - Fifty-five experts from 16 countries have collaborated on a new consensus statement on the management of achondroplasia (ACH), a genetic disorder that interferes with bone growth and causes dwarfism (short stature). ACH is the most common skeletal dysplasia that is estimated to affect one in 20,000 children born worldwide.

The recommendations were published in the *Nature Reviews Endocrinology* journal, addressing the need to standardize medical, functional, and psychosocial care for people with ACH across all major life stages to improve clinical outcomes and quality of life.

Of the 55 renowned experts, five come from Nemours Children's Health, the worldwide leader for the complete medical and surgical management for children with ACH.

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The four other Nemours Children's Health experts on the panel are: pediatric orthopedic surgeon and Chair of Orthopedics, William Mackenzie, MD; pediatric neurosurgeon, Jeffrey Campbell, MD; pediatric anesthesiologist Mary Theroux, MD; and pediatric otolaryngologist, Jenna Briddell, MD.

The consensus statement addresses the entire lifespan of people born with ACH, including recommendations for diagnosis, counseling, and pregnancy of women with ACH or those carrying a baby with ACH. The recommendations also cover multidisciplinary care management for infants, children, adolescents, and adults for many common conditions that are unique to people with ACH. The statement outlines how various specialties ranging from orthopedics to otolaryngology to psychology should be mindful of the care they provide to these patients.

Among many recommendations, the authors provide guidance for various medical sub-specialties to address common health challenges of people with ACH, including spinal stenosis, hearing loss, obesity, and sleep and mental health problems.

The consensus statement can be found online in *Nature Reviews Endocrinology.*

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Savarirayan, R., Ireland, P., Irving, M. *et al.* International Consensus Statement on the diagnosis, multidisciplinary management and lifelong care of individuals with achondroplasia. *Nat Rev Endocrinol* (2021). https://doi.org/10.1038/s41574-021-00595-x

About Nemours Children's Health

Nemours Children's Health is one of the nation's largest multistate pediatric health systems, including two free-standing children's hospitals and a network of nearly 75 primary and specialty care practices. Nemours Children's seeks to transform the health of children by adopting a holistic health model that utilizes innovative, safe, and high-quality care, while also caring for the health of the whole child beyond medicine. Nemours Children's also powers the world's most-visited website for information on the health of children and teens, Nemours KidsHealth.org.

The Nemours Foundation, established through the legacy and philanthropy of Alfred I. duPont, provides pediatric clinical care, research, education, advocacy, and prevention programs to the children, families, and communities it serves.

For further information: Christine Vaughan, cvaughan@thereisgroup.com; Nancy D'Argenio, Nancy.dargenio@nemours.org,302-377-3146

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