



Sentynl Therapeutics Recognizes Menkes Disease Awareness Month, Committed to the Development of Assays for Early Diagnosis of Patients with Menkes Disease

SOLANA BEACH, CA. and CALIFORNIA, MD, Nov. 15, 2021 /PRNewsire/ – Sentynl Therapeutics, Inc. ("Sentynl") a US-based biopharmaceutical company focused on bringing innovative therapies to patients living with rare diseases, joins the global Menkes disease community including the Menkes Foundation ("Menkes Foundation") in recognizing the month of November as Menkes Disease Awareness Month. In support of the patients and families affected by this devastating disease, Sentynl is reinforcing its financial and human resource commitments toward facilitating earlier diagnosis of patients with Menkes disease. At the heart of Sentynl's efforts is the establishment of early screening for Menkes disease, including newborn and high-risk screening.

Recognizing that most patients with Menkes disease experience delayed or missed diagnoses that may affect patient outcomes, Sentynl is advancing initiatives aimed at providing an earlier diagnosis of the disease. These include:

- Collaborating with the world-leading laboratory on the development of a novel newborn screening test, including facilitating the collection of whole blood samples from patients with Menkes disease for assay development and validation, with the aim of universal screening for all babies in the first days of life.
- Advocating for the inclusion of the *ATP7A* gene to the commercially available genetic test panels that will aid in the diagnosis of Menkes patients.

Sentynl's Chief Executive Officer, Matthew Heck, said "Early diagnosis is critical to Menkes disease patients and their caregivers. Our company is proud to support the development of new screening assays while advocating for the addition of Menkes-related genetic markers to standard genetic testing."

Drew and Jamie Eckman, Founders of the Menkes Foundation stated that "one of the key factors in our decision to create the Foundation nearly fifteen years ago, was to achieve a clear pathway for early diagnosis and subsequent treatment. It will be a significant milestone in the fight against Menkes when newborn screening is fully implemented. We are proud to collaborate with Sentynl Therapeutics in promoting awareness for Menkes disease."

About Menkes Disease

Menkes disease is a rare X-linked recessive pediatric disease caused by gene mutations of copper transporter ATP7A. The minimum birth prevalence for Menkes disease is believed to be 1 in 34,810 live male births, and potentially as high as 1 in 8,664 live male births, based on recent genome-based ascertainment (Kaler SG, Ferreira CR, Yam LS. Estimated birth prevalence of Menkes disease and ATP7Arelated disorders based on the Genome Aggregation Database (gnomAD). Molecular Genetics and Metabolism Reports 2020 June 5;24:100602). The condition is characterized by distinctive clinical features, including sparse and depigmented hair ("kinky hair"), connective tissue problems, and severe





neurological symptoms such as seizures, hypotonia, failure to thrive, and neurodevelopmental delays. Mortality is high in untreated Menkes disease, with many patients dying before the age of three years old. Milder versions of ATP7A mutations are associated with other conditions, including Occipital Horn Syndrome and ATP7A-related Distal Motor Neuropathy. Currently, there is no FDA-approved treatment for Menkes disease and its variants.

About Sentynl Therapeutics

Sentynl Therapeutics is a US-based biopharmaceutical company focused on bringing innovative therapies to patients living with rare diseases. The company was acquired by the Zydus Group in 2017. Sentynl's highly experienced management team has previously built multiple successful pharmaceutical companies. With a focus on commercialization, Sentynl looks to source effective and well differentiated products across a broad spectrum of therapeutic areas to address unmet needs. Sentynl is committed to the highest ethical standards and compliance with all applicable laws, regulations, and industry guidelines. For more information, visit <u>www.sentynl.com</u>.

About the Menkes Foundation

For more information about the Menkes Foundation, please visit www.themenkesfoundation.org.

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