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# Emmes and MedGenome Launch Genomics Strategic Partnership Focused on Advancing Rare Disease Research

Rockville, MD – November 15, 2021 – Emmes, a global, full-service Clinical Research Organization (CRO) dedicated to supporting the advancement of public health and biopharmaceutical innovation, today announced a partnership with MedGenome aimed at accelerating breakthrough treatments, powered by human genomics, for rare disease patients.

“This is an exciting opportunity to partner with the leading genetic testing laboratory in India and South Asia to use our collective expertise to help bring faster and more innovative treatments to patients around the world who are suffering from rare diseases and desperately awaiting new therapies,” said Emmes Chief Executive Officer Dr. Christine Dingivan.

“The unmatched potential to build comprehensive and curated disease specific cohorts will leverage the power of large data sets to design smarter research protocols and to reduce the time it takes to identify rare disease patients for clinical trials. Ultimately, we hope this will result in more successful treatment outcomes.”

During its recognition of Rare Disease Day on March 5, 2021, the U.S. Food and Drug Administration noted, “Patients with rare diseases often have few or no treatment options. In 2020, we continued to see significant progress in the development of treatments for rare diseases, also known as orphan products.” In 2020, the FDA approved 32 novel drugs and biologics that had an orphan drug designation.

Traci Clemons, Ph.D., Emmes’ Chief Research Officer, explained that the two companies would collaborate to combine patients’ epidemiologic, phenotypic and genomic data into custom

disease registries to enhance study design, support patient recruitment, and create standard control arms for advanced statistical models of treatment effect.

"There are so many rare diseases and, at the same time, a very small global pool of potential patients for these clinical trials," she said. "Creating these disease registries across high population regions will give us an even greater opportunity to identify and recruit patients with these very rare diseases into clinical trials. These cohorts will, in a sense, offer a customized data resource for potential research sponsors, from biotech firms to large pharmaceutical companies and government research institutions."

Earlier this month, Emmes launched a new rare disease center, blending its expertise in biostatistics, data management and clinical research with Orphan Reach's rare disease patient and clinical trial experience. Emmes acquired the UK-based Orphan Reach in May.

According to a recent article in *Scientific American*, "Only 5% of the 7,000 known rare diseases have an approved treatment, making patients with rare diseases collectively one of the most underserved communities in medicine today."

Some of the initial rare diseases that the Emmes/MedGenome partnership will address include hemophilia, Duchenne muscular dystrophy and muscular atrophies, and retinitis pigmentosa.

MedGenome Services CEO Dr. Vedam Ramprasad, said, "Few people realize that India and South Asia have the world's largest population of people affected by rare and inherited disease. Given the high unmet need of these patients and families, we are dedicated to expanding support and opportunities for the rare disease community in South Asia to contribute to, and benefit from, the substantial treatment advances being made in rare disease globally."

He added, "Rare disease clinical trials face substantial recruitment and regulatory challenges globally. Our rare disease alliance with Emmes is positioned to directly mitigate these challenges and is a natural extension of MedGenome's substantial investment to support rare disease patients and clinicians in South Asia."

Dr. Christine Dingivan concluded, "There is no clear CRO market leader in this space. Our acquisition of Orphan Reach, the creation of our new rare disease center, and now this strategic partnership with MedGenome, solidifies our leadership standing in rare disease drug development."

**About MedGenome**

MedGenome is a genomics-driven research and diagnostics company with a mission to expand access to personalized medicine in South Asia and other emerging markets and help improve global health. Its unique access to genomics data matched with clinical and phenotypic data provides insights into rare and complex diseases at the genetic and molecular level to facilitate research advances and personalized healthcare. MedGenome is the market leader for genetic diagnostic testing in India. For more information, go to: https://research.medgenome.com/

**About Emmes**

Founded in 1977, Emmes is a global, full-service Clinical Research Organization dedicated to excellence in supporting the advancement of public health and biopharmaceutical innovation. The company's clients include numerous agencies and institutes of the U.S. federal government and a wide range of biotechnology, pharmaceutical and medical device companies throughout the world. To learn more about how our research is making a positive impact on human health, go to the Emmes website at www.emmes.com.