FOR IMMEDIATE RELEASE

Miranda's Mission Joins WAGR Warriors and The International WAGR Syndrome Association to Form the Miranda Morris WAGR Spectrum Research Fund at Children's Hospital of Philadelphia

Research fund will be dedicated to unraveling intricate connections between genetic makeup and observable traits in individuals with WAGR syndrome

[JAMISON, PA] FEBRUARY 20, 2024 - Miranda's Mission is pleased to announce its partnership with WAGR Warriors and The International WAGR Syndrome Association (IWSA) to form the Miranda Morris WAGR Spectrum Research Fund at Children's Hospital of Philadelphia (CHOP). This fund will support research focused on determining the connections between genetic makeup and observable traits in individuals with WAGR syndrome. WAGR syndrome is a rare genetic condition, with cases occurring in about one in every 500,000 to 1 million births, that can affect children and is typically characterized by four clinical areas: Wilm's Tumor, Aniridia, Genitourinary problems, and Range of developmental delays. With such a rare disease, developing a comprehensive clinical description of the disorder has been particularly challenging.

Through this collaboration, the team will launch an innovative Genotype-Phenotype Study. This groundbreaking research works to shed light on the relationship between genotype and phenotype, ultimately advancing the understanding of human health and paving the way for personalized healthcare solutions for individuals with WAGR.

The Miranda Morris WAGR Spectrum Research Fund will support this study, which will be conducted by a team of researchers led by Jennifer M. Kalish, MD, PhD, pediatric geneticist at Children's Hospital of Philadelphia, within the Center for Childhood Cancer Research and the Division of Human Genetics in partnership with the Genetic Diagnostic Laboratory at the University of Pennsylvania. These investigators will use various sets of genetic data and attempt to correlate them with various phenotypic characteristics. By exploring the intricate interplay between genes and observable traits, the study seeks to uncover patterns, markers, and potential genetic determinants that influence health outcomes.

"There is something special about Miranda's Mission partnering with WAGR Warriors and the IWSA, as all our missions are centered around enhancing and preserving the lives of not only children and adults with WAGR, but also their families. With the establishment of the Miranda Morris WAGR Spectrum Research Fund, our hope is to offer families a clearer idea of what lies ahead and a firmer understanding of how their diagnosis will progress." Beth Morris, President, Miranda's Mission.

“The work that we do to further understand the WAGR spectrum would not be possible without the collaboration and support of patients and their families,” said Dr. Kalish, Assistant Professor, Division of Human Genetics and Researcher, Center for Childhood Cancer Research, Children’s Hospital of Philadelphia. “We are incredibly grateful for their ongoing commitment to working with us to find answers and improve awareness and quality of care for patients with WAGR spectrum. This study, and others that follow, will allow us to realize the genetic markers associated with different phenotypes and allow us to develop more personalized healthcare.”

Establishment of this fund was made possible by the generosity of many families and donors, all of whom are personally affected by WAGR syndrome. The Miranda Morris WAGR Spectrum Research Fund is intended to be an ongoing and active fund that can support future WAGR syndrome research projects. Miranda’s Mission invites the public, healthcare professionals, and the scientific community to stay updated on the progress on the Genotype-Phenotype Study through updates on Miranda’s Mission website at mirandasmission.org and social media.

For media inquiries, please contact Beth Morris, President of Miranda’s Mission at beth.morris@mirandasmission.org.

Miranda’s Mission is a non-profit organization that is focused on raising money to stimulate research and promote awareness of the rare disease community, specifically WAGR syndrome. Our hope is to engage the medical community and strengthen the relationship between physicians and families, while working to enhance the lives of those affected by WAGR syndrome and other rare genetic diseases.