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FOXG1 Research Foundation Names Dr. Brandon M. Henry Chief Medical Officer

FOR IMMEDIATE RELEASE

FOXG1 Research Foundation Names Brandon M. Henry, M.D., Chief Medical Officer as FRF-001 Advances Toward First-in-Human Clinical Trial

New York — February 20, 2026 — The FOXG1 Research Foundation (FRF), the parent-led nonprofit advancing disease-modifying therapies for children and families impacted by FOXG1 syndrome, today announced the appointment of Brandon M. Henry, M.D., as Chief Medical Officer. In this role, Dr. Henry will lead FRF's clinical strategy across the Foundation's therapeutic portfolio, including clinical oversight of FRF-001, the organization's investigational AAV gene therapy program, as it advances toward a first-in-human, multi-site, international clinical trial that has been cleared by the U.S. Food and Drug Administration (FDA) to begin.

Dr. Henry is a physician–scientist specializing in the clinical development of AAV gene therapies for rare and ultra-rare disorders, with experience guiding complex pediatric programs from preclinical translation through IND submission and clinical development. Most recently, he served as Medical Director of the Cell and Gene Therapy Center of Excellence at IQVIA, where he led medical strategy for global gene therapy programs across multiple indications. He has authored more than 400 peer-reviewed publications and has been recognized among the World's Top 2% Scientists (Stanford/Elsevier) and as a Clarivate Highly Cited Researcher.

FRF is advancing a distinctive approach to drug development, with the Foundation serving as the independent sponsor of a multi-site, international gene therapy clinical trial—enabled by a

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therapies—expertise that is especially critical in first-in-human pediatric gene therapy programs.

“Brandon is exactly the kind of physician–scientist you want guiding a first-in-human pediatric AAV program—rigorous, deeply experienced, and relentlessly focused on patient safety,” said Dr. Gai Ayalon, who brought Dr. Henry onto the FRF gene therapy clinical team. “What makes FRF extraordinary is that the sponsor is the patient community itself. Brandon understands both the scientific complexity and the responsibility that comes with this model, and he is the right leader to help carry this program forward across international sites.”

“Bringing Brandon onto our leadership team is a defining moment for FRF and for families living with FOXG1 syndrome,” said Nicole Johnson, Co-founder and Executive Director of the FOXG1 Research Foundation. “Rare disease patients face the greatest unmet need in medicine. For conditions as ultra-rare as FOXG1, traditional pharmaceutical economics often leave families waiting. We refused to sit on the sidelines, and we’re pioneering a new model to independently advance a treatment all the way through patient clinical trials—at a fraction of the time and cost—creating a path that other rare disease communities can follow. Brandon brings the depth of gene therapy clinical development experience and safety-first leadership to help us execute FRF-001 at the highest level.”

“I’m honored to join the FOXG1 Research Foundation at this pivotal moment,” said Dr. Henry. “FRF has pioneered a disciplined and efficient blueprint for parent-led drug development that is changing what’s possible for ultra-rare diseases. My priority is to advance FRF’s clinical programs with an uncompromising commitment to safety, regulatory alignment, and meaningful outcomes for children and families—starting with FRF-001 as it moves toward first-in-human clinical evaluation.”



About Brandon M. Henry, M.D.

Dr. Brandon M. Henry, M.D., is a physician–scientist specializing in the clinical development of AAV gene therapies for rare and ultra-rare disorders. His work bridges academic and industry domains, with a focus on advancing clinical development strategies for

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Dr. Henry brings deep expertise in AAV vector biology, CNS-directed delivery, immune risk mitigation, and long-term safety monitoring, with extensive experience designing and executing complex pediatric gene therapy trials. He has led multiple AAV programs across academic, biotech, and nonprofit settings, guiding assets from preclinical translation through IND submission, clinical development, and toward registration, with a particular emphasis on rigorous safety frameworks, novel endpoint development, and regulatory alignment for transformative neurologic therapies.

Prior to joining the FOXG1 Research Foundation, Dr. Henry served as Medical Director of the Cell and Gene Therapy Center of Excellence at IQVIA, where he led medical strategy for global gene therapy programs across multiple indications. He has authored more than 400 peer-reviewed publications and has been recognized for several years among the World's Top 2% Scientists (Stanford/Elsevier) and as a Clarivate Highly Cited Researcher, reflecting sustained impact in translational and clinical science. His work centers on translating complex gene therapy science into rigorous, patient-focused clinical programs that responsibly advance transformative therapies for children with severe genetic neurologic diseases.

About the FOXG1 Research Foundation

The FOXG1 Research Foundation is a global parent-led nonprofit organization dedicated to improving the lives of every patient and everyone impacted by FOXG1 syndrome by advancing life-changing therapies and strengthening support for families worldwide. FRF is dedicated to accelerating rare disease drug development—with a new approach that cuts both time and cost by a fraction and creates a path forward for countless rare disease communities.

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