Cozen O'Connor Patent Attorneys Represent, Pro Bono, Nonprofits Established by Parents of Children with Ultra-rare Genetic Disorder

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WASHINGTON, D.C., October 14, 2019 — Cozen O'Connor patent attorneys Jeff Townes and Hongling Zou represent, pro bono, three partner nonprofits established by parents of children with the ultrarare, and potentially fatal, alternating hemiplegia of childhood (AHC). The three partner nonprofits, Cure AHC, Hope for Annabel, and Alternating Hemiplegia of Childhood Foundation, needed help to secure patents for its gene-therapy project.

The nonprofits raised money, including much of it from parents of affected children, to hire a molecular biologist to develop a therapy that administers a nucleic acid sequence encoding a protein that attempts to restore the lost neurological function. Townes and Zou drafted a patent application covering the novel technology, which was filed both as a U.S. application and international application, in April 2019.

Both Townes and Zou have backgrounds in chemistry and work with clients in the life sciences industry. "This subject matter is in line with our backgrounds and experience," said Townes, who joined Cozen O'Connor in 2018. "These nonprofits are working on cutting-edge gene-therapy technology like our clients and, most importantly, they are helping the families of children suffering from these very rare diseases." While the nonprofits needed a patent to prohibit others from using the invention without their permission, their goal is not profit, but the best chance at a treatment and, someday, cure for children with AHC. "The hope and expectation of our clients is that their control of this important invention will incentivize larger and more well-funded entities working on a cure to join their efforts," continued Townes. "In exchange for a license to use the invention, the larger entities may either join our client's research efforts, agree to share data, or do something else that will help find a cure."

AHC is a genetic neurodevelopmental disorder caused by mutations of one of the genes that code for a subunit of the body's critical sodium potassium pump. This mutation interferes with the body's ability to fire nerve cells, causing uncontrollable muscle spasms, pain, temporary paralysis, difficulty breathing and other symptoms, and may lead to permanent brain damage or death. At the moment, there is no effective cure or treatment for the disease.

Simon Frost, head of Cure AHC as well as co-founder of Hope for Annabel, is featured in this Washington Post article, which further describes the disease and the families' challenges and efforts.

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