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For Immediate Release

HUSBAND AND WIFE RETURN TO STAGE TO SUPPORT CHILDREN AFFECTED BY DAUGHTER'S RARE GENETIC DISEASE

Revival of Their Annual Performance of AR Gurney's *Love Letters* Will Benefit Columbia University's Center for Rare Pediatric Genetic Diseases

Vagelos Education Center, 104 Haven Ave
ONE NIGHT ONLY: Wednesday, August 22, at 7:00 PM

***July 31, 2018*—**On August 22, Sally Jackson and Luke Rosen return to the stage for a special, one-night performance of AR Gurney's *Love Letters.* Veteran actors and founders of KIF1A.org, Jackson and Rosen will revive this tradition to shine a light on children affected by rare genetic diseases and benefit the TREATMENT program within the Center for Rare Pediatric Genetic Diseases at Columbia University Medical Center.

Jackson and Rosen first performed *Love Letters* at the Acorn Theatre in 2004 as a special benefit for Broadway Cares: Equity Fights AIDS. The show was a success, so Jackson and Rosen made it an annual event, staging productions over the years to benefit The Harlem Children's Zone, New York Public Library, The Y, Actors Fund, and The Northfield Mount Hermon School. The tradition stopped when Jackson and Rosen decided to devote full attention to rare disease advocacy and finding treatment for children with rare genetic diseases.

In 2016, doctors at Columbia diagnosed Jackson and Rosen's four-year-old daughter, Susannah, with KIF1A Associated Neurological Disorder (KAND). At the time, Susannah was one of only a handful of children in the world known to have this condition. Jackson and Rosen dedicated themselves full-time to caring for their daughter and finding answers about her rare disease. They have since overcome remarkable obstacles, building an unprecedented patient community and kick-starting research into virtually unknown conditions and related diseases.

In pursuit of answers and a cure, Sally and Luke founded **KIF1A.org**. With very little known about KIF1A and related disorders, Wendy Chung's team at Columbia joined the families on a mission to discover treatment. Upon learning that for scientists to understand the KIF1A gene mutation and disease they require mouse models that cost tens of thousands of dollars each, Sally and Luke created the *#WeNeedAMouse* social media campaign. This campaign was seen by The Jackson Laboratory, who secured the required funding for this vital research tool. When the foundation learned that establishing a patient registry and biobank would require a sample size of at least 100 patients (at the time there were less than 50 known cases of KAND), they set about finding affected families around the world.

Today, 141 children diagnosed with KAND have found a community at the Center for Rare Pediatric Genetic Diseases at Columbia University Medical Center. Building on a partnership between KIF1A.org and Columbia University, their families are playing an active role in discovery, and Jackson and Rosen hope the event will shine a light on those around them.

“This event brings together a community of passionate people willing to do everything possible for children with rare genetic diseases,” said Luke Rosen. “Bringing together the patient community, the scientific community and the theater community is a powerful phenomenon.”

“Sally and Luke have shown incredible leadership and epitomize the powerful partnerships that are possible to accelerate research to finding new treatments for rare genetic diseases. They have catalyzed the community to make advances in KIF1A that will help us understand not only KIF1A Associated Neurological Disorder but also other related genetic conditions,” says Wendy Chung, MD, PhD.

Love Letters is about a fifty-year love affair carried on primarily through letters, written in and about a world where letter writing was very much an essential mode of communication, especially between men and women. A finalist for the Pulitzer Prize for Drama, the classic play covers the decades-long relationship between Andy and Melissa. Reading the lifetime of letters they exchange, we follow them through the years. *Love Letters* will surely stay with you long after you leave the theater.

Tickets are available for suggested donation of $50 at
https://events.columbia.edu/cal/event/showEventMore.rdo
More information at KIF1A.org.

About KIF1A.org
KIF1A.org is a patient-led foundation started by parents dedicated to finding a cure for children living with KIF1A Associated Neurological Disorder (KAND). KIF1A.org connects families around the world and works to make sure every child has access to Whole Exome Sequencing, a genetic test allowing physicians to identify extremely rare disease-causing genetic mutations. By identifying children with KIF1A-related disorder, treatment for this rare disease will emerge.

About KIF1A Associated Neurological Disorder
KIF1A is a molecular motor protein vital to brain function. Mutations of KIF1A cause a neurodegenerative disorder with a progressive course. The disease is associated with cognitive impairment, cerebellar atrophy, ataxia, spastic paraplegia, optic nerve atrophy and epilepsy. KIF1A-related disorder is a new disease, and research is rapidly underway to discover treatment. Every day we are closer to understanding KIF1A and how brain function is disrupted by mutations in the gene. Accelerating this research will lead to the development of new treatments and supports for individuals with KIF1A Associated Neurological Disorder.

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