



**FOR IMMEDIATE RELEASE**

### **National Organization for Rare Disorders Appoints California State Ambassadors**

**CALIFORNIA – January 14, 2020**—The National Organization for Rare Disorders (NORD)<sup>®</sup> and its advocacy arm, the Rare Action Network (RAN)<sup>SM</sup> have appointed Earl Cole (Los Angeles, CA) and Zhanzhi “Mike” Hu (Union City, CA) as ambassadors for the State of California. In this capacity, Earl and Mike will work with patient, medical and research organizations in the state as well as with rare disease advocates to raise awareness of rare disease and to champion legislation that will benefit the rare disease community of California.

Earl’s motivation to serve is because he was diagnosed with a rare hip bone disease, called Legg-Calvé-Perthes disease, at the age of six. There is still no known cause or cure for Perthes disease, which affects 5 out of every 100,000 children. Earl is the Founder and President of the Perthes Kids Foundation, the largest and most influential organization dedicated to advocacy, research, and support for families affected by this particular rare disease, worldwide. As someone who has lived with the effects of a rare disease for most of his life, Earl is now fighting for other people dealing with rare disorders, through patient advocacy, health legislation, and national research initiatives.

Mike is motivated to serve because he is a father of three boys, the older two born with a rare genetic disease called Mucopolysaccharidosis Type II (MPS II, aka Hunter Syndrome). As a molecular diagnostic test developer, after witnessing the better outcome of his younger son who was diagnosed and treated at an earlier age, Mike recognized the critical role of early diagnosis of rare disorders in boosting treatment effectiveness. He has been a passionate advocate for radical improvements in the current newborn screening system and is dedicated to the battle against rare disorders.

Volunteer state ambassadors are a vital part of the effort to address rare diseases. Many important decisions related to health care that affect the 1 in 10 Americans with rare diseases are made at the state level, including prescription drug cost-sharing, newborn screening coverage, Medicaid and Children’s Health Insurance Program (CHIP) eligibility, and medical foods coverage. NORD is the leading independent nonprofit committed to the identification, treatment, and cure of rare diseases. In collaboration with the international community, NORD is the official U.S. host and sponsor of Rare Disease Day<sup>®</sup>, a global awareness day to educate and engage the public, elected officials, legislative staff and the media. The L.A. Clippers have selected NORD as their charity for their upcoming game against the Philadelphia 76ers on Sunday, March 1, 2020 in honor of Rare Disease Day. More information on the game, and how to get tickets, may be found on the California Rare Action Network website [RareCA.org](http://RareCA.org).

According to the National Institutes of Health (NIH), a disease is rare if it affects fewer than 200,000 Americans. There are an estimated 25-30 million Americans living with a rare disease.

There are more than 7,000 rare diseases, 90 percent of which have no treatment. Often, research gets funded by the families and friends of patients or by patient organizations.

The Rare Action Network, powered by the National Organization for Rare Disorders (NORD), serves to connect and empower a unified network of individuals and organizations with tools, training and resources to become effective advocates for rare diseases through national and state based initiatives across the United States. We stand for equitable access to timely diagnosis, treatment and care for every person impacted by a rare disease.

For more information about the NORD California Rare Action Network, go to [www.RareCA.org](http://www.RareCA.org). To search for information about rare diseases, visit NORD's website, [www.rarediseases.org](http://www.rarediseases.org).

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**Contact:**

Earl Cole, California Rare Action Network Volunteer State Ambassador [earl.cole@rareaction.org](mailto:earl.cole@rareaction.org)

Mike Hu, California Rare Action Network Volunteer State Ambassador [mike.hu@rareactionn.org](mailto:mike.hu@rareactionn.org)

NORD Media Contact: Laura Mullen, Associate Director, Communications and PR [lmullen@rarediseases.org](mailto:lmullen@rarediseases.org)