

DEPARTMENT OF PEDIATRICS

Division of Pediatric Cardiology

November 4, 2009

Dear Health Care Professional:

About 1% to 4% children with severe to profound sensorineural hearing loss have a rare genetic disorder called the Jervell and Lange-Nielsen Syndrome (JLNS). JLNS is the autosomal recessive form of Long QT Syndrome. Patients with JLNS tend to become symptomatic early and have worse outcomes if untreated. Early detection of JLNS may lead to early effective treatment to prevent sudden death or devastating cardiac events.

We are conducting a research study called "Screening for Jervell and Lange-Nielsen Syndrome". This research project is funded by the National Institutes of Health (NIH) as a part of the American Recovery and Reinvestment Act (ARRA) program. Our goal is to work with the California Newborn Hearing Screening Program to identify infants with hearing loss who may be at risk for JLNS and sudden death. Your patient was found to have sensorineural hearing loss. We have sent a copy of the study flyer (attached) to the family in order to recruit your patient for study participation.

If you or your patients wish to get more information about the research project, please call me at (310) 222-4000, or you can go to: www.infant-heart.com. We appreciate your kind assistance.

Sincerely yours,

Ruey-Kang Chang, MD, MPH
Principal Investigator for "Screening for Jervell and Lange-Nielsen Syndrome"
Associate Professor, UCLA
Chief, Harbor-UCLA Pediatric Cardiology
1000 West Carson Street, Box 491
Torrance, CA 90509
Tel: (310) 222-4001; Fax: (310) 222-4006
Email: rkchang@ucla.edu