

Dear Parent or Family Member:

Many children with PHACES association have abnormalities in the large arteries that supply blood to the brain. We have begun a formal study of these arterial abnormalities using a technique referred to as transcranial Doppler imaging (TCDI). TCDI allows us to take pictures of the intracranial arteries and measure their respective blood-flow velocities. As such, we can characterize the cerebral vascular anomalies present at birth and identify subsequent arterial changes. Unlike other conventional forms of pediatric brain imaging, TCDI does not require sedation or injection of potentially harmful contrast agents. Studies are performed in the office as the child lies comfortably in a parent's lap. An initial evaluation takes approximately 90 minutes. Follow-up exams take between 30-60 minutes. The frequency of follow up will be based on the family's proximity to the Columbia University Medical Center in New York City.

We invite children of all ages for evaluation. However, formal study participation requires serial TCDI in patients without history of prior stroke, four months of age or younger. All children must undergo a standard evaluation for PHACES syndrome including brain MRI with angiography (MRA) and echocardiography. Study participation is free of charge. Unfortunately, we are unable to defray travel or parking expenses for families at this time.

Please contact Dr. Heyer directly with study questions at (212) 342-2900 or by e-mail (gheyer@neuro.columbia.edu). If you are unsure whether your child meets diagnostic criteria for PHACES syndrome, we will be happy to discuss his or her specific case. We look forward to hearing from you.

Sincerely,

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