NC DEPARTMENT OF HEALTH AND HUMAN SERVICES

ROY COOPER • Governor
KODY H. KINSLEY • Secretary
HELEN WOLSTENHOLME • Interim Deputy Secretary for Health
MARK T. BENTON • Assistant Secretary for Public Health
Division of Public Health

Memo

To: North Carolina Newborn Screening Stakeholders

From: Scott M. Shone, PhD, HCLD(ABB) Director, NC State Laboratory of Public Health
Kelly Kimple, MD, MPH, FAAP, Section Chief, Women's and Children's Health

Date: February 14, 2022

Re: **Newborn Screening for X-Linked Adrenoleukodystrophy (X-ALD)**

Starting February 14, 2022, the North Carolina Newborn Screening Program will begin screening all newborn screening specimens submitted to the North Carolina State Laboratory of Public Health (NCSLPH) for X-Linked Adrenoleukodystrophy (X-ALD). X-ALD is a genetic disorder that affects the nervous system and the adrenal glands. Symptoms and onset vary, and may include neurological problems, seizures, learning disabilities, and trouble with coordination and eating, among others.

Newborn screening for X-ALD will be integrated into the standard newborn screening panel and results will be included on all NCSLPH Newborn Screening reports issued starting February 15, 2022. Reports are provided in hardcopy form and are also available via the NCSLPH Clinical and Environmental Lab Results (CELR) online portal.

Screening results that suggest elevated risk for X-ALD will be communicated to the newborn's health care provider by the UNC Division of Genetics and Metabolism Follow-up Program. The Follow-up Program will provide consultation services and recommendations for follow-up testing.

In addition to X-ALD, the Newborn Screening Program is working towards the implementation of screening this year for Pompe Disease and Mucopolysaccharidosis Type I (MPS-I). Additional information on the implementation of screening for these disorders will be shared later this year.

For questions about newborn screening laboratory testing for X-ALD, please contact the NCSLPH Newborn Screening Laboratory at 919-807-8938.