State of California—Health and Human Services Agency
Department of Health Services

California Department of Health Services

DIANA M. BONTÁ, R.N., Dr. P.H.
Director

Gray Davis
Governor

May 22, 2003

To: Pediatric Care Providers

Dear Health Care Provider:

This is to advise you that the California Newborn Screening Program's pilot project in Tandem Mass Spectrometry (MS/MS) will end on June 13, 2003. The mandated Newborn Screening Program tests for phenylketonuria (PKU), hypothyroidism, galactosemia, sickle cell anemia and hemoglobin disorders will not change.

Since January 2002, the MS/MS pilot project has operated under state statute and one time funding of $3.9 million to determine whether MS/MS technology could detect additional genetic conditions in newborns beyond those tested in the mandated Newborn Screening Program. The Genetic Disease Branch has been offering this test to those families who consented to participate in the evaluation at no additional charge. Over 320,000 newborns have been tested in this supplementary, voluntary evaluation project. At this time, the one-time funds for this pilot project have been exhausted and testing will end effective June 13, 2003.

PLEASE DO NOT OFFER TANDEM MASS SPECTROMETRY SUPPLEMENTAL SCREENING TO ANY FAMILY AFTER JUNE 13, 2003. SPECIMENS RECEIVED AFTER THAT DATE OF COLLECTION WILL ONLY RECEIVE ROUTINE NEWBORN TESTS (PKU, HYPOTHYROIDISM, GALACTOSEMIA, AND HEMOGLOBIN DISORDERS).

Prenatal care providers and hospitals have been instructed to use the original lavender colored "Important Information for Parents" pamphlet or remove the central light purple section and the consent form with the yes/no stickers from the dark purple "Important Information for Parents" booklet for their patients who will deliver their babies after June 13th. These will provide parents with information about the mandatory newborn screening program only.

We have been advised that the medical community, hospital administration and third party payers may receive questions such as: (1) will this testing will be offered by private laboratories (2) if so, which laboratories are these, and (3) will this testing and follow-up services be covered benefits by private health insurance. To assist in dealing

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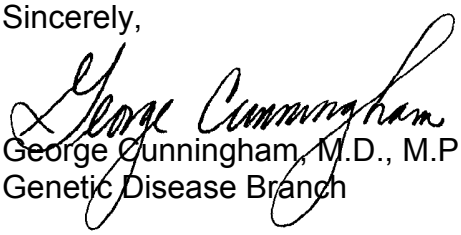
with these questions, we have included a list of potential private testing resources. Please note that this list is informational and does not constitute endorsement by the Department of Health Services.

The Genetic Disease Branch will be preparing an evaluation of the results of the pilot project over the next year and will share it with all providers that participated in the project.

We want to thank all the physicians and hospital staff and their Institutional Review Boards for all their contributions to the pilot project and their commitment to providing optimal care for their patients. The Genetic Disease Branch will continue to work with the health care community, families, and other interested parties to ensure that California newborns receive the highest standard of care.

Sincerely,



George Cunningham, M.D., M.P.H., Chief
Genetic Disease Branch

Enclosures