PROCEDURE FOR NY PARENTS TO REQUEST PARTIAL DESTRUCTION OF BABY DNA - NEW YORK DEPT OF HEALTH *

From: Victoria A Popson <vap02@health.state.ny.us>
To: xxxxxx
Sent: xxxxxxx
Subject: Specimen Destruction

Dear xxxxx;

…I am writing you with instructions on having your child’s newborn screening specimen destroyed. The written request must include:

1. The infant's name, date of birth, gender, mother's name and any AKA's (also known as), and the name of the hospital of birth along with any other information that as [sic] requested by the Newborn Screening Program in order to insure accurate identification.

2. A clear statement of parental expectations regarding specimen use;
   a. Specimen usage disallowed for all research purposes
   b. Specimen usage allowed only under certain circumstances (per parent's request and provision of explanation).
   c. Specimen destruction.

3. Original signature of both parents.

4. Parental contact information (address/phone number).

The specimen will be pulled from general storage and placed into medical waste. The parent's are notified in writing that the specimen(s) has/have been destroyed. The original request is scanned in to an electronic case file.

LIMITATIONS:
At all times, one full blood spot is to remain on the card. Requestors are notified by the Director or an appointee that the remaining specimen cannot be released. [emphasis added]

All written requests should be submitted to:

Michele Caggana, Sc.D., FACMG
Director, Newborn Screening Program
New York State Department of Health
Wadsworth Center
P.O. Box 509
Albany, New York 12201-0509

Victoria A. Popson
Public Health Rep. II
NYS Dept. of Health
Newborn Screening Program
518-473-7552 ext. 07498

* NOTE FROM CCHF: Since NY State retains one bloodspot despite parent request for destruction, parents may wish to explicitly request destruction and a prohibition on all uses, including research.