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Director & State Health Officer

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



EDMUND G. BROWN JR.  
Governor

Dear Parents:

We received your request indicating that you would like to have your child's newborn screening blood specimen destroyed. The attached form needs to be completed and returned to us before we can follow-up with your request. However, before you complete this form, please read the following information that describes the California Newborn Screening Program and the reasons why the Genetic Disease Screening Program (GDSP) stores blood specimens.

Infants in California are screened for a wide variety of genetic disorders at birth, most of which, if detected early and treated, can prevent mental retardation, severe neurological problems, irreversible comas, and even death. Currently, approximately 1 in 600 births are diagnosed with one of the disorders screened for by the GDSP. GDSP also provides important follow-up services for infants identified through this public health screening program. This follow-up ensures timely medical intervention which has been documented to dramatically improve health outcomes for children diagnosed with one of the screened disorders.

The GDSP is required by state and federal statute, to maintain confidentiality of the dried blood specimens, which are stored in a highly secured facility. The actual specimen collection cards contain a unique non-identifying number and no other information about the newborn. Only authorized program staff has access to the Screening Information System database which contains the initial information provided to the GDSP so that we can interpret and report out the newborn screening test result to the newborn's pediatrician and hospital of birth.

There are several reasons why the newborn dried blood specimen card is stored by the program:

1. To have a large pool of de-identified (anonymous) specimens to use to develop tests for new disorders. The process of developing a new screening test for a new disorder typically involves the use of up to 100,000 "practice" de-identified specimens.
2. Using specimens that come from the California population is particularly important. Use of these dried blood spots has enabled GDSP to develop new tests and to refine the existing screening program on an ongoing basis, utilizing the demographics (race/ethnicity) of California infants to improve the accuracy of the test.
3. The baby's screening tests can be repeated if needed without getting another blood sample from the baby.
4. The baby's sample is properly stored and available to parents for other health-related testing (for example, in the case of unexplained deaths such as Sudden Infant Death Syndrome, SIDS, or the specimen is required for diagnosis of a rare disorder).
5. The baby's sample is available to parents to help identify a missing or deceased child.

Furthermore, newborn dried blood specimens containing personal identifying information are never released to researchers or outside agencies without prior approval of the parents (for example, in the case of a formal research study) and the GDSP adheres to all rules regarding human subjects research as described by State and Federal law. Contrary to recent news reports you may have seen, the Program does not store the dried blood specimens for the purpose of gathering DNA. The blood spots are not provided to any state or national forensic DNA data banks.

The GDSP takes the confidentiality requirements extremely seriously and there are severe penalties for the unlawful release of any information that identifies a parent or infant. These penalties include significant fines and other financial penalties, and incarceration. Since the inception of this program, there has never been any instance of a privacy breach.

The GDSP considers the use of these dried blood specimens an invaluable resource, without which the addition and refinement of testing for specific disorders would have been delayed significantly; resulting in affected newborns not receiving timely medical intervention. California is considered a national leader in newborn screening and use of the dried blood specimens has been a key component of our success. This screening program benefits all California newborns, families and the communities in which they live.

If after reading this information, you would still like to have your child's blood specimen destroyed, please complete the attached form and mail it, fax, or scan and email it to:

Robin L. Cooley, MSc  
Genetic Disease Screening Program  
California Department of Public Health  
850 Marina Bay Parkway, F175, Mailstop 8200  
Richmond, CA 94804  
Phone: (510) 412-1500  
Fax: (510) 412-1547  
Email: [Robin.Cooley@cdph.ca.gov](mailto:Robin.Cooley@cdph.ca.gov)

Your request could take up to 30 days. After the specimen is destroyed, we will send you an email or a letter indicating that your request was completed. If you have any additional questions, please feel free to contact me via phone, email, or post.

Sincerely,

California Biobank Coordinator  
Genetic Disease Screening Program