

## Raiders of the lost blood spots

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Blood Spots Assessed by CDC

Almost every newborn in the United States is pricked on the heel within hours of birth for a few drops of blood that are then tested for conditions like PKU, sickle cell anemia, and cystic fibrosis. But then the sample is often put on small piece of blotter paper and filed away by the state. Few parents know about these millions of residual dried blood spots.

Alex Kemper, Duke professor of pediatrics and community and family medicine, spoke at the Genomics and Personalized Medicine Forum on the "raiders" of these lost <u>blood spots</u>, researchers who might use them to improve public health. Along with issues of science, he addressed the negative public reaction to research using stored blood spots. "Why does the government have my DNA?"



Dried blood spots have many uses beyond <u>early detection of diseases</u>. They can be used to improve quality of current screening tests and new screening approaches. In a few cases, dried blood spots have been valuable in forensic analysis to identify an abducted child. In this era of increasingly personalized medicine, being able to use blood spots for genomic analysis would provide answers to new research questions, Kemper said.

However, the differences in the way blood spots are stored present research challenges. Kemper is very interested in how environmental toxins affect children's health. When his research team attempted to use dried blood spots to study how flame-retardants affect thyroid problems, they ran into a major problem. Because blood spots are often stored in an environment more like the warehouse from Raiders of the Lost Ark than a controlled lab environment, the specimens were too contaminated to use for research.

Besides the inherent quality concerns, the public is wary of researchers using blood spots because of the lack of consent and confidentiality. (See "<u>Texas Newborn Bloodspot Saga</u>") Should researchers be able to use blood spots from infants without consent from <u>parents</u>? Should the blood spots be anonymized to protect privacy even though anonymization limits the types of research that can be performed?

These questions do not have easy answers.

States differ on legislation about the retention, confidentiality, and parental control of blood spots. Some states have no rules at all. Kemper claimed that many of these laws are currently in "a state of flux" because of pending lawsuits and changing public perceptions. As the rules change, one thing is almost certain: improving the genetic literacy of the public is essential to advancing uses of dried blood spots.



## Provided by Duke University

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