Children's Advocacy Institute

August 23, 2002

Office of Regulations
Department of Health Services
714 P Street, Room 1000
P.O. Box 942732
Sacramento, CA 94234-7320

Re: Written Comment Regarding DHS' Notice of Emergency Rulemaking for Newborn Screening Program Fee Increase (R-54-01E)

To the Office of Regulations:

The Children's Advocacy Institute (CAI), located at the University of San Diego School of Law, seeks to improve the health, safety, and well-being of California's children. CAI advocates in the legislature to make laws, in the courts to interpret laws, before administrative agencies to implement laws, and before the public to educate and build support for laws to improve the status of children statewide and nationwide. CAI educates policymakers about children's needs for economic security, adequate nutrition, health care, education, quality child care, and protection from abuse, neglect, and injury.

CAI is concerned with both procedural and substantive issues relating to DHS' emergency rulemaking increasing, for a second time since December of 2001, the fees paid by third parties for genetic screening of newborns.

DHS is bound by the directives of the Administrative Procedure Act, where the method and use of emergency rulemaking are described as follows:

> "[I]f a state agency makes a finding that the adoption of a regulation ...is necessary for the immediate preservation of the public peace, health and safety or general welfare, the regulation may be adopted as an emergency regulation...Any finding of an emergency shall include ...a description of the specific facts showing the need for immediate action." Government Code section 11346.1(b).

Government Code section 11346.1(h) further provides that OAL "shall not file an emergency regulation with the Secretary of State *if the emergency regulation is the same as or substantially equivalent to an emergency regulation previously adopted by that agency*, unless the director expressly approves the agency's readoption of the emergency regulation" (emphasis added).

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On December 28, 2001, OAL approved DHS' regulatory changes associated with the first newborn screening fee increase, from $42 to $56, on an emergency basis. That first round of emergency rulemaking was followed by the public comment period, and then by OAL's approval of the permanent changes on May 16, 2002. On June 28, 2002, OAL approved the regulatory changes associated with the second fee increase proposed by DHS, from $56 to $60, again on an emergency basis. Repeated use by DHS of the emergency rulemaking procedures is inappropriate, especially in light of the agency's presumed ability to anticipate a $17 million administrative cost for upgrading its failing information technologies support system. Further, why did DHS fail to anticipate a need for an additional fee increase at its last emergency rulemaking on this issue in December of 2001? Such a large administrative cost should be anticipated prior to becoming an "emergency" situation, which DHS claims will result in discontinuation of important health services.

DHS has violated the mandate of the APA by repeatedly claiming "emergency" status in lieu of filing a proposed rulemaking through the normal channels, which allows greater time and opportunity for public feedback before the rule is approved. DHS reports that it received no public comment on the December 2001 fee increase (from $42 to $56), which is not surprising given the agency's improper use of the emergency rulemaking process. Once a rule is in place the importance of public input is severely diminished.

Turning to the substantive issues, DHS reported that the prior emergency regulation would have a fiscal effect on private individuals without health insurance and insurance companies providing health care services, estimated at $4,447,000 (317,668 births multiplied by $14). DHS estimated the fiscal effect on both state and federal governments would total $2.8 million combined (200,000 births multiplied by $14). DHS estimates the current emergency regulation will have a $1,420,000 effect on the uninsured and insurance companies.[1] DHS estimates the additional fiscal impact on state and federal governments will be $361,000 each.[2] Added to the previous increase from $42 to $56, the total fiscal impact on third party payers in the last eight months will be over $5.8 million, a 42.8% increase. CAI is unaware of any other government program fee increase of this magnitude that so heavily impacts the poor.

CAI is concerned with two aspects of DHS' financial figures. One, there is no breakdown of the group entitled "third party payers" to show the financial impact on the uninsured, which is the group hardest hit by any fee increases. Of the $5,867,000 fiscal

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[1] $1,420,000 divided by a $4 increase is 355,000 births, which is greater than the estimated 317,668 births used by DHS in its December 2001 emergency rulemaking.

[2] Again, the agency's estimate of the number of births in the December 2001 emergency rulemaking (200,000) is different than the current rulemaking ($722,000 divided by $4 is 180,500 births). The difference is not explained.

impact on third party payers, how much of that burden will be carried by our state's uninsured versus insurance companies? Second, it is unclear how DHS calculated the fiscal effect on state and federal government versus third party payers. In the first round of increases, according to DHS' estimated figures, the fiscal effect on government was approximately 63% of the costs to private parties, yet, the second round of increases show the fiscal effect on government to be only 51% of private party costs. The difference is not explained.

Second, CAI is concerned about whether the $17 million expense for "updating and reengineering the information technology support system" is one incurred only by the newborn screening program, or whether the expense will apply to other DHS programs and/or general administrative costs. In other words, does this expense exclusively pertain to the newborn screening program? If not, it would be inappropriate to charge the users of this program for the full cost.

DHS states that the current fee collection rate for this program is 80%. According to DHS figures supporting the December 2001 fee increase, the collection rate has dropped dramatically, from 98% to 80%. Information is not provided on which groups or individuals make up the 20% of current uncollected fees. DHS should be concerned and seek alternative action if, as the numbers show, the uninsured cannot pay for the screening. Certainly, an $18 increase in the span of several months is significant to poor, uninsured mothers. Although no general fund monies, other than those falling under public assistance programs, are expended on this program, perhaps the state's financial burden should be increased to fulfill the legislative intent of the Hereditary Disorders Act, which is to screen each child born in this State in order to prevent or cure certain hereditary disorders, thus, preventing a future burden on the state's health care system. See, e.g., Health and Safety Code sections 124977, 124996 and 125000.

Pursuant to Health and Safety Code section 124977(c)(2), DHS has a duty to analyze costs so that equipment and services are obtained "at the lowest cost consistent with technical requirements for a comprehensive high-quality program." The cost of this program appears to be skyrocketing, judging from the agency's frequent fee increases. An uninsured mother's inability to pay for screening will decrease the quality of health care received by the child.

This rulemaking comes at the same time as the legislature and the governor are considering a dramatic decrease of Medi-Cal provider rates to doctors who treat children. California's reimbursement rates already fall well below the average rate nationwide. The landscape created by our government's current position is that access to the public health system for women and their young children will become increasingly obsolete and

unaffordable. Why not increase the fee for those women covered by insurance or public funds, but retain the lower fee for the uninsured? Or what about a sliding scale fee based upon income to assist the poor?

The entire climate relating to access to medical care for the uninsured continues to worsen. The state is not fully using federal matching funds, yet the uninsured are denied health care and continue to pay additional costs just to receive basic services such as newborn screening. There may come a time when the cost of self-sustaining large, fragmented public health programs will become so great, that it will be more cost effective to implement universal coverage of all children with parental assessment post hoc on a sliding scale based upon income. In the meantime, policymakers of our state should act responsibly and not increase the burden on those who are unable to absorb additional costs.

We appreciate the opportunity to submit our concerns and look forward to a response.

Sincerely,

/s/
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Executive Director of CAI

/s/
DEBRA L. BACK
Attorney for CAI