Approved: February 28, 2003
Date

MINUTES OF THE SENATE PUBLIC HEALTH AND WELFARE.

The meeting was called to order by Chairperson Senator Susan Wagle at 1:30 p.m. on February 5, 2003 in Room 231-N of the Capitol.

All members were present except: Senator David Haley
Senator Chris Steineger

Committee staff present: Ms. Emalene Correll, Legislative Research Department
Mr. Norm Furse, Revisor of Statutes
Ms. Margaret Cianciarulo, Administrative Assistant

Conferees appearing before the committee: Dr. Mike Moser, Director of Health, KDHE
Mr. Norm Hess, Director of Program Services for the Greater Kansas Chapter of the March of Dimes
Mr. Larry Edmunds, Epidemiologist, National Center for Birth Defects on Developmental Disabilities, Center for Disease Control (CDC)

Others attending: See attached guest list

Introduction of Bills

Upon calling the meeting to order, Chairperson Wagle recognized Dr. Mike Moser, Director of Health, KDHE to introduce a proposed administration bill relating to the childhood lead poisoning prevention program. He stated under the proposed legislation that the sunset date of the Kansas law be extended to 2010 which is the national target goal for elimination of childhood lead poisoning. Also, that statutory authority be obtained to promulgate state rules relative to renovation of pre-1978 housing, case management of lead poisoned children, and lead safe work practices in commercial and industrial structures all in accordance with national guidelines. A copy of his proposed administration bill is (Attachment 1) attached hereto and incorporated into the Minutes by reference. Senator Salmans made a motion to hear the proposed legislation. Senator Brownlee seconded the motion and the motion carried.

The Chair then introduced three bill requests from Senator Emler that were requested from pharmacists in his area:

1.) A bill requiring that all health benefit plans apply the same coinsurance, copayment, and deductible factors to all drug prescriptions filled under the plan;

2.) Non resident pharmacies which violate the nonresident pharmacy law (63-1657) would be subject to penalties under the Kansas consumer protection act; and

3.) A bill which would require benefit prescription mangers to be licensed. This would provide oversight of pharmacy benefit management companies.

A copy of the above is (Attachment 2) attached hereto and incorporated into the Minutes by reference.

A discussion ensued among the Committee clarifying that the above are controversial and for introduction only as Committee bills. The Chair indicated to the Committee that she did not commit to having a hearing on the proposed legislation. The Chair then made a motion to hear the proposed legislation. Senator Brungardt seconded the motion and the motion carried.

Presentation on Birth Defect Registry

The Chair then recognized Mr. Norm Hess, Director of Program Services for the Greater Kansas Chapter of the March of Dimes who stated he was here today to ask the Committee for their support of a bill that has already been introduced into the Committee, to authorize the establishment of a fully operational state birth defects information system. Highlights of Mr. Hess's presentation ranged from: providing statistics, March of Dimes mission, prevention, epidemiological research being a critical step in developing cost-effective strategies, to Kansas being one of seven states that does not provide a mechanism for systematic confirmation and follow-up. A copy of his presentation is (Attachment 3) attached hereto and incorporated into the Minutes by reference.

Mr. Hess then gave an overview of the Ohio law regarding birth defects information systems, that:

1.). Lists specific purposes;
2.) Minimizes duplication of reporting by hospitals, physicians, and birthing centers plus, establishes appropriate confidentiality measures which gives parents and guardians of children of birth defects, the option of having information withdrawn from the registry;
3.) Delineates membership of voluntary council to assist and advise the Department of Health in establishing an implementation of the system; and
4.) Includes a clause making implementation contingent upon appropriations or other funding sources.

The Chair then recognized Mr. Larry Edmonds, Epidemiologist at the National Center on Birth Defects in Developmental Disabilities, Center for Disease Control (CDC), who stated that their role in birth defects work on surveillance prevention and research. He then gave an overview of birth defects, public health importance, what is a good system, what the States are doing, and what CDC does to support the States. A copy of his slide presentation is (Attachment 4) attached hereto and incorporated into the Minutes by reference.

Written testimony was also provided by Ms. Jamey Kieffer, Director, Children with Special Health Care Needs Program, Kansas Department of Health and Environment. A copy of her testimony is (Attachment 5) attached hereto and incorporated into the Minutes by reference.

The Chair thanked the conferees for their presentation then asked the Committee for questions or comments. Senators Barnett, Wagle, Harrington, Salmans, Steineger, and Barnett asked a range of questions from: how do we involve geneticists with a state with no money, the availability of federal money, future coop agreements (what does Kansas need to do to join), sharing information for a common good, is this similar to the Alzheimer's organization, what software programs work and don't work, are private foundations funding, pilot studies, Kansas poor track record on computer projects, to a comment of so much data already made available.

Adjournment

As it was going on 2:30 p.m., the Chair concluded the meeting by again thanking Mr. Edmonds and Mr. Hess for traveling to Kansas and sharing their information with the Committee. Adjournment time was 2:30 p.m.

The next meeting is scheduled for February 6, 2003.

SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

GUEST LIST

DATE: Wens. 2-5-03

NAME	REPRESENTING
Michelle Peterson	Kansas Governmental Consulting
Geffrey L. Bogus	March of Dimes — Topeka Div.
Fred Patton	March of Dimes - Kansas Chapter
Mark Schreiber	Self
Christina Collins	KMS
Steve Kearney	MOD
Sheila Walker	MOD
Larry Edmonds	CDC Atlanta GA
Jamey Kieffer	KDHE
Linda Kenyon	KDHE
Michael Moser	KDHE
Barry Brooks	KDHE
Jane Stueve	KDHE
Carolyn S Nelson	KDHE
Marie Ann Rover	KAHP
David Owen	Homeless Coal Home
Jim Byrnes	Sen. Salmans Ass

Be it enacted by the legislature of Kansas:

Section 1. K.S.A. 2001 Supp. 65-1,200 is hereby amended to read as follows: Citation of act. K.S.A. 2001 Supp. 65-1,200 to 65-1,214, inclusive, of this act shall be known and may be cited as the ~~residential childhood~~ *child and adult* lead poisoning prevention act.

Section 2. K.S.A. 2001 Supp. 65-1,201 is hereby amended to read as follows: Definitions. As used in the ~~residential childhood~~ *child and adult* lead poisoning prevention act:

(a) "Abatement" means any measure or set of measures ~~designed to~~ *which* permanently ~~eliminate~~ *eliminates* lead~~-based paint~~ hazards ~~as defined in the federal program~~.

(b) "Accredited training program" means a training program that has been accredited by ~~the federal program or~~ the secretary to present training courses to individuals engaged in lead~~-based paint~~ activities.

(c) "Business entity" means a company, partnership, corporation, sole proprietorship, association, or other business concern.

(d) "Certificate" means an authorization issued by the secretary permitting an individual to engage in lead~~-based paint~~ activities.

(e) "Commercial and industrial properties" means, but is not limited to, any factory, plant, refinery, warehouse, steel edifice, building or complex of buildings, which include activities that are generally recognized as commercial or industrial by local zoning authorities in this state, but shall not include:

1) Housing built before 1978,

2) Child occupied facilities, and

3) Government facilities

~~(e)~~ *(f)* "Federal program" means subpart L, lead-based paint activities of 40 CFR part 745, as in effect on the effective date of this act.

~~(f)~~ *(g)* "Lead-based paint" means paint or other surface coatings that contain lead equal to or in excess of one milligram per square centimeter or more than 0.5% by weight.

~~(g)~~ *(h)* "Lead~~-based paint~~ activities" means the inspection, assessment and abatement of lead~~-based paint~~ *and lead hazards*~~, including the disposal of waste generated therefrom~~*, and any investigation for the determination of the presence of lead in soil, paint, water or dust on residential, commercial or industrial properties.*

~~(h)~~ *(i)* "License" means an authorization issued by the secretary permitting a business entity to engage in lead~~-based paint~~ activities.

~~(i)~~ *(j)* "Public agency" means any state agency or political or taxing subdivision of the state and those federal departments, agencies or instrumentalities thereof which are not subject to preemption.

~~(j)~~ *(k)* "Secretary" means the secretary of health and environment.

~~(k)~~ *(l)* "Residential dwelling" means a detached single family dwelling or a single family dwelling unit in a structure that contains more than one separate residential dwelling unit used as a place of residence for habitation by an individual or the individual's immediate family, or both.

(m) "Residential real property" means real property on which there is situated one or more residential dwellings used or occupied, or intended to be used or occupied, in whole or in part, as the home or residence of one or more persons.

(n) "Renovation activity" means activities that disturb more than two square feet of paint.

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~~(l)~~ *(o)* "Habitation" means a place of abode or residence constructed before 1978 where individuals eat, sleep and reside.

~~(m)~~ *(p)* "Immediate family" means spouse, parent, stepparent, *adult child,* child, *foster child,* stepchild, *grandchild, niece, nephew,* ~~or~~ sibling*, or any combination thereof.*

Section 3. K.S.A. 2001 Supp. 65-1,202 is hereby amended to read as follows: Development and implementation of prevention program; licensure training and inspections; fees; rules and regulations. The secretary shall administer the provisions of the ~~residential childhood~~ *child and adult* lead poisoning prevention act. In administering the provisions of the ~~residential childhood~~ *child and adult* lead poisoning prevention act, the secretary shall be authorized to:

(a) Develop and implement a ~~childhood~~ *child and adult* lead poisoning prevention program as necessary to protect the health of the ~~children~~ *people* of Kansas, which may include provisions to:

(1) Investigate the extent of ~~childhood~~ *child and adult* lead poisoning in Kansas;

(2) develop a data management system designed to collect and analyze information on ~~childhood~~ *child and adult* lead poisoning;

(3) develop and conduct programs to educate health care providers regarding the magnitude ~~and severity~~ of ~~and the necessary responses to~~ lead poisoning in Kansas.

(4) Implement procedures relevant to the case management of elevated blood lead levels.

~~(4)~~ *(5)*issue recommendations for the methods and intervals for blood lead screening and testing of children, taking into account recommendations by the United States centers for disease control and prevention, except that no child shall be screened or tested if the child's parent or guardian objects in writing on the ground that such ~~screening or~~ testing is contrary to the parent's or guardian's religious beliefs and practices;

~~(5)~~ *(6)*develop and issue health advisories urging health care providers to conduct blood lead ~~screening of children~~ *testing*;

~~(6)~~ *(7)*encourage health care providers to ensure that parents and guardians of children are advised of the availability and ~~advisability~~ *feasibility* of ~~screening and~~ testing for lead poisoning;

~~(7)~~ *(8)*develop a program to assist local health departments in identification and follow-up of cases of elevated blood lead levels in children and other high-risk individuals; and

~~(8)~~ *(9)*in consultation with appropriate federal, state and local agencies, develop a comprehensive public education program regarding environmental lead exposures and lead poisoning by:

(A) Identifying appropriate target groups that are in a position to prevent lead poisoning or reduce ~~the number of children who are exposed~~ *exposure* to lead;

(B) assessing the information needed for each of the target groups and determine the best means of educating the members of each target ~~groups~~ group; and

(C) disseminating the information to the target groups in an effective manner.

(b) adopt rules and regulations necessary for the administration of the ~~residential childhood~~ *child and adult* lead poisoning prevention act including, but not limited to, licensure of business entities and public agencies, certification of individuals, accreditation of training programs, on-site inspections and requirements, notification and record keeping, procedures and work practice standards relating to lead~~-based paint~~ activities as are necessary to protect the public health and safety;

(c) adopt by rules and regulations a reasonable schedule of fees for the issuance and renewal of certificates and licenses, training program accreditations and on-site inspections. The fees shall be periodically increased or decreased consistent with the need to cover the direct and indirect costs to administer the program. At no time shall such fees exceed those charged by the United States environmental protection agency for the same or similar regulatory programs. The fees shall be based upon the amount of revenue determined by the secretary to be required for proper administration of the provisions of the ~~residential childhood~~ *child and adult* lead poisoning prevention act. State and local health department personnel certifying for the purpose of environmental investigation of lead poisoned children shall be exempted from ~~licensure~~ *certification* fees;

(d) conduct on-site inspections of procedures being utilized by a licensee during an actual abatement project and conduct inspection of the records pertaining to the ~~residential childhood~~ *child and adult* lead poisoning prevention act;

(e) adopt rules and regulations regarding the distribution of lead hazard information to owners and occupants of housing prior to conduction renovation activities in housing;

(f) adopt rules and regulations for renovation activities in pre-1978 housing.

(g) adopt rules and regulations for lead activities in commercial and industrial properties.

Section 4. K.S.A. 2001 Supp. 65-1,203 is hereby amended to read as follows: Licensure or certification to perform lead~~-based paint~~ activities.

(a) A business entity or public agency shall not engage in a lead~~-based paint~~ activity unless the business entity or public agency holds a license issued by the secretary for that purpose.

(b) Except as otherwise provided in the ~~residential childhood~~ *child and adult* lead poisoning prevention act, no individual shall engage in lead-based paint activities unless the individual holds a certificate issued by the secretary for that purpose. In order to qualify for a certificate, an individual must have successfully completed an accredited training program and pass a third party exam as required by the secretary. Any individual who owns and resides in a residential dwelling may perform lead~~-based paint~~ activities within such residential dwelling even though such individual does not hold a certificate for that purpose under the ~~residential childhood~~ *child and adult* lead poisoning prevention act. All work performed by such individual owner of a residential dwelling must be performed in accordance with state and federal guidelines or statutes, or both.

(c) Any business or public agency that owns or leases a nonresidential dwelling may perform lead~~-based paint~~ activities within such facility even though such business or public agency does not hold a license for that purpose under the ~~residential childhood~~ *child and adult* lead poisoning prevention act. All work performed by a business or public agency on such facility must be performed in accordance with state and federal guidelines or statutes, or both.

Section 5. K.S.A. 2001 Supp. 65-1,204 is hereby amended to read as follows: Same; qualification requirements. In order to qualify for a license, a business entity or public agency shall:

(a) Ensure that each employee or agent ~~of the business entity or public agency~~ who will engage in a lead~~-based paint~~ activity is certified;

(b) demonstrate to the satisfaction of the secretary that the business entity or public agency is capable of complying with all requirements, procedures and standards of the United

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States environmental protection agency, the United States occupational safety and health administration and the secretary, as applicable, to lead-~~based paint~~ activities;

(c) comply with all rules and regulations adopted by the secretary under the ~~residential childhood~~ *child and adult* lead poisoning prevention act; and

(d) allow representatives of the secretary, after identification, to enter and inspect any habitation *or commercial or industrial properties*, or property on which a habitation *or commercial or industrial property* is situated at any reasonable time with consent of the owner or under search warrant for the purpose of inspecting lead ~~based paint~~ activities as required in order to implement provisions of the ~~residential childhood~~ *child and adult* lead poisoning prevention act.

Section 6. K.S.A. 2001 Supp. 65-1,205 is hereby amended to read as follows: Remittance of fees. The secretary shall remit all moneys received from the fees established pursuant to the ~~residential childhood~~ *child and adult* lead poisoning prevention act to the state treasurer in accordance with the provisions of K.S.A. 75-4215, and amendments thereto. Upon receipt of each such remittance, the state treasurer shall deposit the entire amount in the state treasury to the credit of the lead-based paint hazard fee fund established in K.S.A. 2001 Supp. 65-1,206, and amendments thereto.

Section 7. K.S.A. 2001 Supp. 65-1,206 is hereby amended to read as follows: Lead-based paint hazard fee fund; sources of revenue; expenditures.

(a) There is established in the state treasury the lead-based paint hazard fee fund. Revenue from the following sources shall be deposited in the state treasury and credited to the fund:

(1) Fees collected under the ~~residential childhood~~ *child and adult* lead poisoning prevention act for licensure and certification to engage in lead-~~based paint~~ activities, accreditation of training programs and fees for evaluation of abatement projects;

(2) any moneys recovered by the state under the ~~residential childhood~~ *child and adult* lead poisoning prevention act, including administrative expenses, civil penalties and moneys paid under any agreement, stipulation or settlement;

(3) any moneys collected or received from public or private grants and from gifts and donations; and

(4) interest attributable to investment of moneys in the fund. (b) Moneys deposited in the fund shall be expended only for the purpose of administering the ~~residential childhood~~ *child and adult* lead poisoning prevention act and for no other governmental purposes.

(c) On or before the 10th day of each month, the director of accounts and reports shall transfer from the state general fund to the lead-based paint hazard fee fund interest earnings based on:

(1) The average daily balance of moneys in the lead-based paint hazard fee fund for the preceding month; and

(2) the net earnings rate of the pooled money investment portfolio for the preceding month.

(d) All expenditures from the fund shall be made in accordance with appropriation acts upon warrants of the director of accounts and reports issued pursuant to vouchers approved by the secretary for the purposes set forth in this section.

Section 8. K.S.A. 2001 Supp. 65-1,207 is hereby amended to read as follows: Denial, suspension or revocation of license or certificate or accreditation of training program, when; suspension of ~~abatement~~ *lead activities* program; administrative review.

(a) The secretary may refuse to issue a license or may suspend or revoke any license issued under the ~~residential childhood~~ *child and adult* lead poisoning prevention act if the secretary finds, after notice and hearing conducted in accordance with the provisions of the Kansas administrative procedure act, that the applicant or licensee has:

(1) Fraudulently or deceptively obtained or attempted to obtain a license;

(2) failed at any time to meet the qualifications for a license or to comply with any rules and regulations adopted by the secretary under the ~~residential childhood~~ *child and adult* lead poisoning prevention act;

(3) failed at any time to meet any applicable federal or state standard for lead~~-based paint~~ activities; or

(4) employed or permitted an uncertified individual to work on a lead~~-based paint~~ activity.

(b) The secretary may refuse to issue a certificate or may suspend or revoke any certificate issued under the ~~residential childhood~~ *child and adult* lead poisoning prevention act if the secretary finds, after notice and hearing conducted in accordance with the provisions of the Kansas administrative procedure act, that the applicant for certificate or certificate holder has:

(1) Fraudulently or deceptively obtained or attempted to obtain a certificate; or

(2) failed at any time to meet qualifications for a certificate or to comply with any provision or requirement of the ~~residential childhood~~ *child and adult* lead poisoning prevention act or any rules and regulations adopted by the secretary under the ~~residential childhood~~ *child and adult* lead poisoning prevention act.

(c) The secretary may deny, suspend or revoke any accreditation of a training program under the ~~residential childhood~~ *child and adult* lead poisoning prevention act if the secretary finds, after notice and hearing conducted in accordance with the provisions of the Kansas administrative procedure act, that the applicant for training program accreditation or training provider has:

(1) Fraudulently or deceptively obtained or attempted to obtain accreditation of a training program;

(2) failed at any time to meet the qualifications to obtain accreditation of a training program or to comply with any rules and regulations adopted by the secretary under the ~~residential childhood~~ *child and adult* lead poisoning prevention act;

(3) failed to maintain or provide information on training programs; or

(4) falsified information, accreditation or approval records, instructor qualification information or other accreditation or approval information required to be submitted by the secretary.

(d) Any individual, business entity or accredited training program aggrieved by a decision or order of the secretary may appeal the order or decision in accordance with the provisions of the act for judicial review and civil enforcement of agency actions.

(e) (1) If the secretary finds that the public health or safety is endangered by the continuation of ~~an abatement project~~ *a lead activity*, the secretary may temporarily suspend, without notice or hearing in accordance with the emergency adjudication procedures of the provisions of the Kansas administrative procedure act, the license of the business entity or public agency or the certificate of any person engaging in such ~~abatement project~~ *lead activity.*

(2) In no case shall a temporary suspension of a license or certificate under this section be in effect for a period of time in excess of 90 days. At the end of such period of time, the license or certificate shall be reinstated unless the secretary has suspended or revoked the license or certificate, after notice and hearing in accordance with the provisions of the ~~residential childhood~~ *child and adult* lead poisoning prevention act, or the license has expired as otherwise provided under the ~~residential childhood~~ *child and adult* lead poisoning prevention act.

Section 9. K.S.A. 2001 Supp. 65-1,208 is hereby amended to read as follows: Noncompliance; notice; duty to meet compliance requirements. Whenever an authorized agency of the secretary finds that any individual, business entity, accredited program or public agency is not in compliance with the ~~residential childhood~~ *child and adult* lead poisoning prevention act or any rules and regulations adopted under the ~~residential childhood~~ *child and adult* lead poisoning prevention act, it shall be the duty of such agent to notify the individual, business entity, accredited program or public agency in writing of such changes or alterations as the agency shall deem necessary in order to comply with the requirements of the ~~residential childhood~~ *child and adult* lead poisoning prevention act and any rules and regulations adopted under the ~~residential childhood~~ *child and adult* lead poisoning prevention act, and the agency shall file a copy of such notice with the secretary. It shall thereupon be the duty of the individual, business entity, accredited program or public agency ~~to make such changes or alterations as are contained in the written notice within five days~~ *to inform KDHE of its corrective plan within 24 hours* from the receipt of such notice.

Section 10. K.S.A. 2001 Supp. 65-1,209 is hereby amended to read as follows: Violations; criminal penalties. Any individual, business entity, public agency or accredited training program which knowingly violates any provision of the ~~residential childhood~~ *child and adult* lead poisoning prevention act or any rules and regulations adopted under the ~~residential childhood~~ *child and adult* lead poisoning prevention act is guilty:

(a) For a first offense, of a class C misdemeanor; and (b) for a second offense or subsequent offense, of a class B misdemeanor.

Section 11. K.S.A. 2001 Supp. 65-1,210 is hereby amended to read as follows: Same; civil penalties; corrective action; appeals; grants to communities to eliminate hazards.

(a) Any individual, business entity, accredited training program or public agency who violates any provision of the ~~residential childhood~~ *child and adult* lead poisoning prevention act or any rules and regulations adopted under the ~~residential childhood~~ *child and adult* lead poisoning prevention act, in addition to any other penalty or litigation provided by law, may incur a civil penalty imposed under subsection (b) in a maximum amount not to exceed $1,000 for the first violation, $5,000 for each subsequent violation and, in the case of a continuing violation, every day such previously notified violation continues shall be deemed a separate violation.

(b) The secretary, upon finding that any individual, business entity, accredited training program or public agency has violated any provision of the ~~residential childhood~~ *child and adult* lead poisoning prevention act or any rules and regulations adopted under the ~~residential childhood~~ *child and adult* lead poisoning prevention act, may impose a civil penalty within the

limits provided in this section upon such individual, business entity, accredited training program or public agency which civil penalty shall be in an amount to constitute an actual and substantial economic deterrent to the violation for which the civil penalty is assessed.

(c) The secretary, upon finding that an individual, business entity, accredited training program or public agency has violated any provision of the residential childhood child and adult lead poisoning prevention act or rules and regulations adopted under the ~~residential childhood~~ *child and adult* lead poisoning prevention act, may issue an order finding such individual, business entity, accredited training program or public agency in violation of the ~~residential childhood~~ *child and adult* lead poisoning prevention act and directing the individual, business entity, accredited training program or public agency to take such action as necessary to correct the violation.

(d) No civil penalty shall be imposed under this section except upon the written order of the secretary after notification and hearing, if a hearing is requested, in accordance with the provisions of the Kansas administrative procedure act.

(e) Any individual, business entity, accredited training program or public agency aggrieved by an order of the secretary made under this section may appeal such order to the district court in the manner provided by the act for judicial review and civil enforcement of agency actions.

(f) Any penalty recovered pursuant to the provisions of this section shall be remitted to the state treasurer and deposited in the lead-based paint hazard fee fund.

(g) The secretary shall use penalties recovered pursuant to the provisions of this section to establish a grant program for communities to conduct activities designed to reduce or eliminate exposure of children to residential lead ~~based paint~~ hazards.

Section 12. K.S.A. 2001 Supp. 65-1,211 is hereby amended to read as follows: Same; additional remedies. Notwithstanding any other remedy and in addition to any other remedy, the secretary may maintain, in the manner provided by the act for judicial review and civil enforcement of agency actions, an action in the name of the state of Kansas for injunction or other process against any business entity or individual to restrain or prevent any violation of the provisions of the ~~residential childhood~~ *child and adult* lead poisoning prevention act or of any rules and regulations adopted under the ~~residential childhood~~ *child and adult* lead poisoning prevention act.

Section 13. K.S.A. 2001 Supp. 65-1,212 is hereby amended to read as follows: Implementation of act by entities engaging in lead ~~based paint~~ activities; when. Licensure, certification or training program accreditation for a business entity, public agency or individual who engages in lead ~~based paint~~ activities shall not be required until such time as the secretary adopts rules and regulations to implement the provisions of the ~~residential childhood~~ *child and adult* lead poisoning prevention act.

Section 14. K.S.A. 2001 Supp. 65-1,213 is hereby amended to read as follows: Statutory audit privilege not applicable. The audit privilege recognized in K.S.A. 2001 Supp. 60-3332 through 60-3339 does not pertain to the ~~residential childhood~~ *child and adult* lead poisoning prevention act.

Section 15. K.S.A. 2001 Supp. 65-1,214 is hereby amended to read as follows: Repeal of act. On July 1, ~~2004~~ 2010, the provisions of K.S.A. 2001 Supp. 65-1,200 to 65-1,214 inclusive, of this act are hereby repealed.

Three Bill Requests – Senator Emler

1. **3rs0565.** A bill requiring that all health benefit plans apply the same coinsurance, copayment and deductible factors to all drug prescriptions filled under the plan.

2. **3rs0261.** Nonresident pharmacies which violate the nonresident pharmacy law (65-1657) would be subject to penalties under the Kansas consumer protection act.

3. A bill which would require benefit prescription managers to be licensed. This would provide oversight of pharmacy benefit management companies.

Senate Public Health & Welfare Committee
Date: February 5, 2003
Attachment 2-1

March of Dimes
Saving babies, together®

ESTABLISHING A

BIRTH DEFECTS INFORMATION SYSTEM

IN KANSAS

Testimony on behalf of the

March of Dimes

Before the Senate Committee on Public Health and Welfare

February 5, 2003

Presented by:

Norm Hess
Director of Program Services
March of Dimes Greater Kansas Chapter

Senate Public Health & Welfare Committee
Date: February 5, 2003
Attachment 3-1

My name is Norm Hess, and I am the Director of Program Services for the Greater Kansas Chapter of the March of Dimes. I am here today to ask for your support of a bill to authorize the establishment of a fully operational state birth defects information system.

The March of Dimes mission is to improve the health of babies by preventing birth defects and infant mortality. Birth defects are not only the leading cause of infant death in America, but also a leading cause of childhood disability. Each year, some 150,000 babies – about 4 percent of live births – are born with a birth defect. KDHE statistics show that there were 38,832 live births in Kansas in 2001. If 4% of babies in Kansas are born with a birth defect, that represents approximately 1,500 babies annually.

The detection of birth defects should not be left to chance. Epidemiological research into the causes of birth defects is a critical step in developing cost-effective strategies to prevent this tragedy. Data is needed to monitor infant health and the incidence of birth defects and to identify communities and populations especially at risk. Such state-based birth defects information systems help health officials assess needs, deliver services, and assess the progress of prevention programs.

According to the Centers for Disease Control and Prevention (CDC), 34 states plus Puerto Rico have some type of birth defects information system, while another 9 states and the District of Columbia are planning one. Kansas is one of seven states that either does not have system or simply collects data from birth certificates and does not provide a mechanism for systematic confirmation and follow-up.

A fully operational state birth defects information system has several compelling benefits. Besides helping to identify incidence and clusters of birth defects, the system would provide a database that would contribute to better health status of infants and children by providing data needed to investigate the causes of birth defects. It would also broaden access and linkages to existing programs and services for children with special health needs, and increase prevention activities related to these conditions. Finally such an information system would foster development of public health programs and enhance community-based health initiatives. Passage of authorizing legislation would demonstrate continued support to ensure implementation and maintenance of our state's system.

Prevention is also integral to the effort to reduce the impact of birth defects on public health. Each year, for example, thousands of children are born with neural tube defects (NTDs) – birth defects of the brain and spinal cord, such as spina bifida and anencephaly. Taking folic acid – a B vitamin – before pregnancy can prevent most NTDs. Because 50 percent of pregnancies in the United States are unplanned, folic acid is recommended for all women of childbearing age.

Preventable birth defects like NTDs underscore the need for programs such as folic acid education. The March of Dimes, along with the CDC, recently completed a national campaign to educate women of childbearing age about the benefits of taking folic acid. During the course of this campaign, we saw a 32% decrease in the incidence of neural tube defects in the United States. Educational programs put into practice knowledge gained from scientific research. The

ability to prevent birth defects saves in economic as well as human terms. The average lifetime cost to care for a single child with a birth defect such a spina bifida is nearly $300,000, according to the California Birth Defects Monitoring Program.

At the federal level, March of Dimes volunteers and staff successfully lobbied the Congress to enact the Children's Health Act of 2000 (P.L. 106-310) and the Birth Defects Prevention Act of 1998 (P.L. 105-168). The Children's Health Act created a National Center on Birth Defects Surveillance and Developmental Disabilities at CDC. The Birth Defects Prevention Act set up a federal program within the CDC to provide surveillance, research, and other services targeted at preventing these birth defects. CDC is working with the states to carry out this initiative through technical assistance, cooperative agreements and collaborative studies. For its part, the March of Dimes continues efforts to secure appropriations for these programs.

The March of Dimes urges you to protect communities in Kansas through a birth defects information system. The volunteers and staff of the March of Dimes look forward to working with you to prevent birth defects.

Norm Hess
March of Dimes Greater Kansas Chapter
4050 Pennsylvania, Suite 141
Kansas City, MO 64111
816-561-0175
nhess@marchofdimes.com

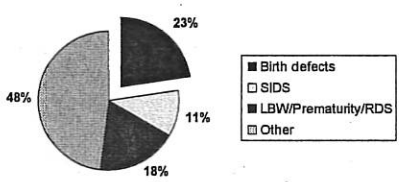
Birth Defects Surveillance, Research, and Prevention

Larry Edmonds
National Center on Birth Defects
and Developmental Disabilities
Centers for Disease Control and Prevention

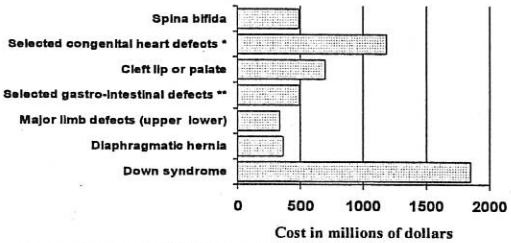
Birth Defects

- Leading cause of infant deaths
- 22% of U.S. infant deaths in 1998
- Contribute substantially to morbidity and long-term disability
- 3-4 % of births have a major defect
- Common in aggregate, but individual defect types rare
- > 70% of unknown etiology
- Costly
- Preventable

Leading Causes of Infant Death, United States, 1996



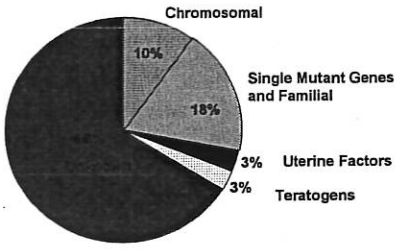
Estimated Lifetime Costs of Selected Birth Defects for Children Born in the United States, 1992



* Truncus arteriosus, transposition of the great vessels, and tetralogy of Fallot only.
** Esophageal atresia/trachea-esophageal fistula, colon or rectal atresia, and gastroschisis only.
Economic Costs of Birth Defects and Cerebral Palsy--United States, 1992. MMWR, Sept 22, 1995.

Senate Public Health & Welfare Committee
Date: February 5, 2003
Attachment 4-1

Causes of Birth Defects Among Affected Infants



From Nelson and Holmes, NEJM January 5, 1989

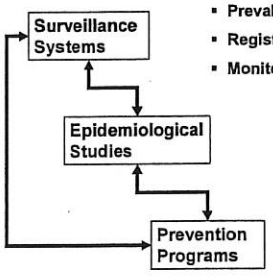
Estimates of adverse reproductive outcomes

- Estimates of adverse outcomes for Kansas– 2000
  - Total births –39,668
  - Number of infants with a Major Malformation – 1190-1587 (3-4%)
    - Number of infants with NTD's –40
    - Number of infants with FAS – 40-80
    - Number of infants with Downs Syndrome – 40
    - Number of infants with Oral-facial Clefts - 60
  - Infant Deaths – 268 (20+% due to birth defects)
  - Developmental Disabilities
    - Mental retardation – 396 (1%)
    - Cerebral palsy –79 (0.2%)

Preventable Causes of Birth Defects

- Maternal condition: Diabetes, phenylketonuria
- Infectious agents: Rubella, toxoplasmosis, syphilis, cytomegalic inclusion disease, varicella
- Prescription drugs: Thalidomide, accutane, valproic Acid, lithium
- Environmental: High dose ionizing radiation, hyperthermia, organic mercury
- Nutrition: Folate deficiency, high dosage of vitamin A
- Substance abuse: Alcohol, smoking, cocaine

CDC's Role in Preventing Birth Defects



- Prevalence rates
- Registry of cases for study or referral
- Monitor prevention
- Risk factors
- Protective factors
- Public concerns
- Prevention strategies
- Public policy
- Education

4-2

BIRTH DEFECT SURVEILLANCE PROGRAMS

History of Birth Defects Surveillance

- 1926 - Earliest Mandated System - New Jersey
- 1960's - International Interest due to Thalidomide
- 1968 - Metropolitan Atlanta Congenital Defects Program started at CDC
- 1974 - Birth Defects Monitoring Program started at CDC
- 1974 - 3 State Programs
- 1998 - National Birth Defects Prevention Act
- 1999 - National Birth Defects Prevention Network
- 2000 – Children's Health Act
- 2003 - 44 State Programs

Public Health Surveillance: The ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice

Monitor: **Watch, observe, control**

Track: **Keep an account of, stay informed about, maintain contact with**

Goals

- Detect time trends, epidemics
- Quantify morbidity or mortality
- Stimulate epidemiological research
- Provide case registry
- Prioritize services
- Guide and evaluate intervention and prevention
- Provide information for education and advocacy

Characteristics of an Effective Surveillance Program

- Comprehensive review of multiple data sources
- Accurate and precise diagnostic criteria
- Appropriate classification schemes
- Timely analysis and dissemination of data
- A large database
- Personal identifiers and confidentiality
- Link with exposure information

Case Definition:

- Definition of major malformations and minor malformations
- Conditions to be excluded
- Other birth defects, biochemical and genetic diseases that should be included
- Age of infants to be included
- Gestation age and/or birth weight criteria
- Include prenatally diagnosed cases

Data Sources

- Vital records
- Hospital records
- Administrative databases
- Special data sources
- Prenatal diagnosis center
- Clinical examination

EVALUATION OF DATA SOURCES

Birth Certificates	
Predictive Value Positive	76%
Sensitivity	28%
Hospital Discharge Data	
Predictive Value Positive	85-95%
Sensitivity	70-90%

Case Ascertainment methods for Identifying Infants with Birth Defects (I)

- Examine every baby born
  - Collaborative Perinatal Project
- Review medical records including hospital data from nurseries, NICU, specialty clinics, laboratories, screening programs
  - Metro Atlanta, Hawaii, Iowa
- Identify records for review with hospital discharge summaries or disease indexes
  - Arizona, California
- Use existing hospital discharge data and outpatient data
  - National BDMP, H-CUP, Connecticut

Case Ascertainment methods for Identifying Infants with Birth Defects (II)

- Legislative mandate for hospital or physician reporting
  - New York, New Jersey
- Linkage of multiple data sources
  - North Carolina, Missouri, Colorado
- Vital Statistics - births, deaths, fetal deaths
- Other data sources - Prenatal diagnosis, Genetic clinics, Medicaid, Special Health Care Needs Programs, physician records, special surveys,

Percentage of infants with birth defects determined by various data sources, North Carolina 1996

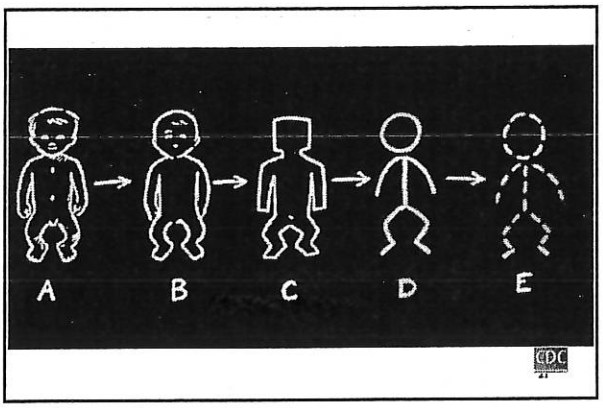
Source	Rate
Sole Source	
Birth Certificates	4.3%
Death Certificates	0.5%
Newborn Medicaid Claim	7.5%
Hospital Discharge	68.2%
Multiple Sources	19.4%
	100.0%

numbers of infants are live born with major defects

Rates of Major Birth Defects Determined by Various Data Sources

Method and Source	Rate
Birth Certificates*	1.5%
Newborn hospital discharge§	4.3 - 7.1%
Mandatory hospital reporting¶	3.4%
Linked data sources **	4.7%
Active hospital surveillance §§	3.2%
Physical exam of infants ¶¶	8.3%

* Birth Certificates - 1996
§ Florida 1996
¶ New York - 1994-96
** North Carolina - 1995-96
§§ MACDP 1995-99
¶¶ Collaborative Perinatal Project - 1959-96



Consideration of the Types of Data to Collect

- Birth defect/ genetic disease data
  - Coding
  - Selection of specific defects
  - Classification of birth defects
- Identifiers
- Demographic data
- Pregnancy data
- Family history data

Confidentiality Procedures

- Moral and legal obligation
- Most States have procedures to protect information
- Many States have procedures to share data
- Design and document office and field procedures
- Sign a confidentiality pledge
- All files and documents locked and password protected
- Separate identifying information from data
- Encrypt of develop algorithm for scrambling identifiers
- All studies involving research must have IRB approval
- All families or patients have the right to refuse to participate in a study or decline services

CDC BIRTH DEFECTS SURVEILLANCE AND RESEARCH ACTIVITIES

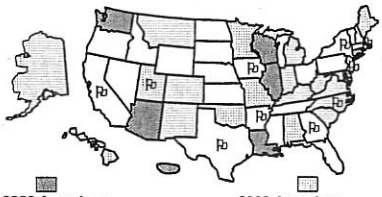
CDC Birth Defects Activities with States

- Provides technical assistance with development of surveillance systems
- Assists with legislative issues, epidemiological use of the data, and cluster investigations
- Offers MACDP as a model for birth defects surveillance
- Facilitates exchange of information between states
- Collaborates on epidemiological studies
- Publishes multi-state surveillance data
- Participates on state advisory committees
- Provides local/regional workshops to address birth defects surveillance issues
- Assists with Abstractors' training

Current Cooperative Agreements for Birth Defects Activities

- Goal: Collect birth defects data and use information for public health programs
- Purpose:
  - Improve quality and timely ascertainment of major birth defects
  - Improve access to care for children with birth defects
  - Improve timely ascertainment of NTD cases
  - Work on prevention and intervention programs
  - Encourage surveillance of prenatally diagnosed cases
- 35 states with cooperative agreements
  - 28 states with surveillance funding (8 states in 9/2000, 20 in 3/2002)
  - 7 states with surveillance and research funding

Cooperative Agreements for BD Activities



Centers for Birth Defects Research & Prevention

Arkansas
California
CDC
Iowa
Massachusetts
New Jersey
New York
North Carolina
Texas
Utah

2000 Awardees

Arizona
Connecticut
Illinois
Louisiana
Puerto Rico
Rhode Island
Washington
Wisconsin

2002 Awardees

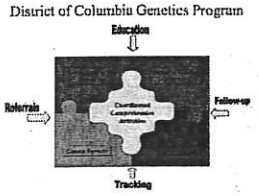
Alabama
Alaska
Colorado
Hawaii
Indiana
Kentucky
Maine
Michigan
Missouri
Minnesota
Montana
New Hampshire
New Mexico
North Carolina
Oklahoma
South Carolina
Utah
Virginia
West Virginia
District of Columbia

Birth Defects Cooperative Agreements - Accomplishments

- 35 operational programs, 10 planning programs
- Accomplishments from the previous cooperative agreements that ended in 2/2002
  - Improved in timely and quality of birth defects data, specifically NTDs (18)
  - Initiated/fine-tuned prenatal surveillance (7)
  - Initiated activities to assist families with NTD-affected pregnancies (14)
  - Formed multi-agency collaborations to carry out prevention and intervention projects (18)
  - Established a system to referral children to services/follow-up to access to care (10)

Birth Defects Cooperative Agreements - Challenges

- Access to data/release of data for intervention activities (HIPAA/FERPA/confidentiality issues)
- Data integration, e.g. technological issues
- Continuous improvement in timely and quality data collection
- Prenatal surveillance
- Continuous momentum of prevention activities and partnership collaboration
- Funding



Future Cooperative Agreements for Birth Defects Activities

- New awards in September 2003
- 8-12 state programs
- Focus: use of data for intervention and prevention as well as evaluation of those activities
- Continue to provide technical support

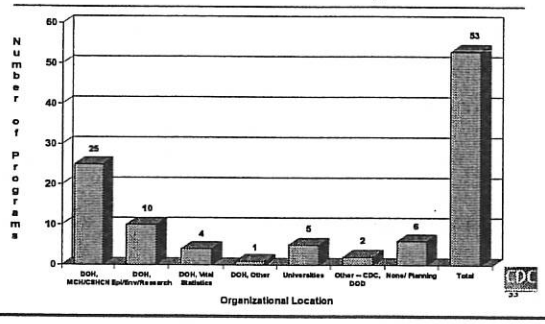
Surveillance Activities at the State Level

- Data are used for:
  - Case-control and descriptive studies
  - Cluster investigations
  - Address community concerns
  - Monitoring rates of birth defects
  - Prevention programs
  - Case identification for early intervention
  - Needs assessment
  - Service planning and evaluation
  - Monitor mandated programs

Current State Activities in Birth Defects Surveillance

Sept. 2001

Organizational Location of State Birth Defects Surveillance Programs



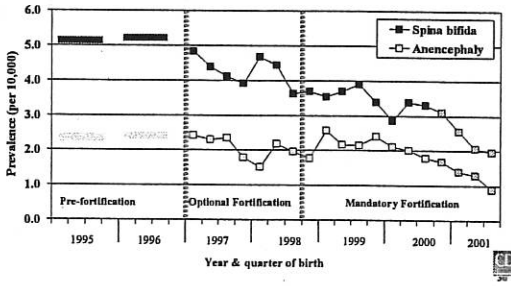
Challenges for surveillance

- Timeliness
- Consistent diagnosis
- Balance quality vs. timeliness
- Confidentiality
- Ability to share data
- Duplication of cases

Data collection methods

- Annual data are reported for 1995 and 1996
- Data are reported by quarter of birth for 1997 to the present
- In each data submission, programs:
  - are given two quarters to ascertain cases before reporting the data
  - have the opportunity to update previously reported data
  - adjust elective pregnancy terminations and fetal deaths for EDD, when possible

Prevalence of spina bifida and anencephaly among all 24 participating surveillance programs



Change in NTD prevalence* (24 programs)

	Pre-fort.	Optional fort.	Mandatory fort.	PR** (95% CI)	% decline
Spina bifida	5.14	4.28	3.47	0.67 (0.63-0.73)	33% (22%)
Anencephaly	2.45	2.11	2.11	0.86 (0.78-0.95)	14% (11%)

* Prevalence per 10,000

**Compares mandatory to pre-fortification prevalence

USING SURVEILANCE DATA

Data presentation
Epidemiologic terms
Descriptive epidemiology
Referral for services and prevention
Etiologic research

Data use and analysis

- Routine statistical monitoring
- Public health program evaluation
- Baseline rates
- Rates by demographic and other variables
- Monitoring outbreaks and cluster investigations
- Time trends
- Epidemiologic studies

Data use and analysis

- Needs assessment
- Service delivery
- Referral
- Grant proposals
- Education/public awareness
- Prevention projects

Planning a State-Based System

- Who gets involved? Interagency coordination
- Development and role of advisory committee
- Goals and objectives
- Needs and resources assessment
- Sources of program support
- Legislation?

Benefits of Legislation

- Authority and language to enforce rules and regulation
- Authority to collect data and contact families
- Mandate hospitals and physicians to report
- Mandate conditions and ages of children to be reported
- Authoritize access to data on individuals but ensure confidentiality
- Designates organization to manage surveillance system
- Provision for initial and continued funding

Legislation Planning and Enactment

- Is Legislation desirable?
- Plan legislation based on goals
- Develop case for legislation and identify support
- Review other state statutes
- Legislation for access to data or mandatory reporting?
- Explicit authority for surveillance function
- Reporting requirement and list of conditions belong in rules and regulation not statute
- Ethical and social issues (confidentiality)

Implementation of Program

- Community and public education
- Implementation plan and time-table
- Cooperation of providers
- Development of study instruments
- Data management and processing – work plan
- Outcomes and utilization and evaluation plans
- Follow-up studies

Potential Funding Sources and Advocates

- **Potential funding sources:**
  - Congressional funding
  - Private foundations
  - Tobacco funds
  - Other sources
- **Advocates:**
  - MOD
  - PEW
  - SBAA
  - Others

Estimated Birth Defects Surveillance Cost by Methods

Birth Defects Surveillance Method	Quality of Data	Cost Per Live Birth	Cost Per Case Ascertained	Total Cost for 60,000 b irths each year
Birth Certificates (1 state)	Poor	—	None	None
Mandatory Hospital Reporting (12 states)- without follow-up	Fair	$1-$5	$25-$125	$60,000 - $250,000
Mandatory Hospital Reporting (11 states) – with follow-up & quality control	Good	$5-$10	$125- $250	$250,000-$500,000
Intensive Surveillance (10 states)	Best	$10-$30	$250-$750	$500,000 - $1,500,000

These are estimates and can vary greatly depending on the specific methodology used.

Current Funding Sources

- General state funds – 21 out of 40 states (52.5%)
- MCH – 15/40 (37.5%)
- Genetic screening revenues – 2/40 (10%)
- CDC grant – 27/40 (67.5%)
- Other federal funding – 7/40 (17.5%)
- Private foundation – 3/40 (7.5%)

K A N S A S

RODERICK L. BREMBY, SECRETARY

KATHLEEN SEBELIUS, GOVERNOR

DEPARTMENT OF HEALTH AND ENVIRONMENT

Hearing on Birth Defects Information System
to
Senate Public Health and Welfare
Presented by
Jamey Kieffer, Director, Children with Special Health Care Needs Program
Kansas Department of Health and Environment

February 5, 2003

Chairperson Barnett and members of the Senate Public Health and Welfare Committee, my name is Jamey Kieffer. I am a nurse and the Director of the Children with Special Health Care Needs Program at KDHE. Since about 1995, I have been involved in the KDHE newborn screening program and in congenital malformations reporting by hospitals.

Thank you for devoting your time to a study of a Birth Defects Information System, a worthwhile subject for the families of Kansas. We applaud your efforts, those of the March of Dimes and the Centers for Disease Control. Several of our staff are here today and we are available to answer any questions you may have with respect to our current efforts.

Senate Public Health & Welfare Committee
Date: February 5, 2003
Attachment 5

DIVISION OF HEALTH
Bureau for Children, Youth & Families
CURTIS STATE OFFICE BUILDING, 1000 SW JACKSON, STE. 540, TOPEKA, KS 66612-1274
Voice 785-291-3368 Fax 785-296-6553 http://www.kdhe.state.ks.us/bcyf