Approved: March 3, 1999
Date

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Garry Boston at 1:30 p.m. on February 22 in Room 423-S of the Capitol.

All members were present except: Representative Brenda Landwehr, Excused

Committee staff present:
Emalene Correll, Kansas Legislative Research
Norman Furse, Revisor of Statutes
June Evans, Secretary

Conferees appearing before the committee:
Sally Finney, Executive Director, Kansas Public Health Association, Inc.
Richard A. Baker, Co-Chair, Kansas Lead Council
Sam Umscheid, Wyandotte County Health Department
Penny Selbee, Kansas Public Health Association
Barry Brooks, Kansas Childhood Lead Poisoning Prevention Program
Dr. Rebecca Gaughan, Otolaryngologist, Olathe
Rebecca J. Aranda, Executive Director., Kansas Commission of the Deaf
Trisha Harrington, LINK, Inc., Hays, Kansas
Keith R. Landis, Christian Science Committee on Publication for Kansas

Others attending: See Attached Sheet

The Chairperson opened the hearing on **HB 2362 - Newborn infant hearing screening tests.**

Staff gave a briefing on **HB 2362.**

Rebecca Aranda, Executive Director of the Kansas Commission of the Deaf and Hard of Hearing (she is deaf) testified in support of **HB 2362**, stating she had severe hearing loss since birth due to her mother having rubella during her first trimester. Her loss of hearing was not diagnosed until the age of two. The technology and knowledge available now was not available in the sixties and loss of hearing was hard to identify. Being diagnosed at age 2 her parents had to work very hard and sacrificed a lot to assist with language development. With today's technology hearing can be identified at birth. **HB 2362** would ensure that all newborns are screened. (See Attachment #1)

Representative Phyllis Gilmore stated she was enthused and honored to introduce Dr. Rebecca Gaughan and she supported **HB 2362.**

Rebecca Gaughan, a practicing otolaryngologist - head and neck surgeon (ear, nose, and throat physician) in private practice in Olathe testified in support of **HB 2362,** stating she was here to testify because she has seen children whose hearing loss was first identified over the age of two. Approximately 1 of every 1000 children born in the United States is born deaf. As many as 900 infants a year in Kansas suffer from undetected hearing loss. New scientific evidence overwhelmingly shows that infants whose deafness is detected early, and certainly within the first six months after birth, can learn to communicate far better than those whose impairment is found later. Studies show that without hearing aids or some type of amplification by at least six months of age, certain brain pathways will close off. By the time children with hearing loss enter the first grade, children identified and treated before six months of age are one or two years ahead of their later identified peers. (See Attachment #2)

The Chairperson asked if there were any opponents to **HB 2362** in the audience. There were no opponents so the Chairperson asked what the committee wished to do with the bill.

Representative Bethell moved and Representative Haley seconded to move **HB 2362** out favorably and put on the consent calendar. The motion carried.

The Chairperson asked if there were any others in the audience that would like to personally give their testimony.

Trisha Harrington, Hays, testified as a proponent to **HB 2362** , stating she had been profoundly deaf since birth. She is employed at LINK, Inc. and also works with Kansas Rehabilitation Services, providing services to people who are deaf and hard of hearing as well as other disabilities. It is of utmost importance to mandate testing of newborn babies in the state of Kansas for potential hearing deficits. Early identification is the key to successful education of death and hard of hearing children. Parents must decide how best to approach their children's education upon learning that their child has a hearing loss. The earlier hearing loss is identified, parents can spend the early months of the child's life assessing whether manual, oral/auditory, or total communications is best for the child. (See Attachment #3)

The following written testimony was distributed: Cheryl Jackson (See Attachment #4); Lorna Alexander, (See Attachment #5); Sara Sack, Ph.D., CCC-SLP, Co-Director of Assistive Technology for Kansas Project, (See Attachment #6); Pamela Cress, Program Coordinator, University of Kansas Affiliated Program at Parsons (See Attachment #7); Glenda Hurter, Speech Pathologist, Myofunctional Therapist, (See Attachment #8); Eileen Patterson, (See Attachment #9); Clysta Beal, Ft. Scott, (See Attachment #10); Lori L. Burns, (See Attachment #11); Heidi Daley, MS,CCC/A, (See Attachment #12); Judith E. Widen, Ph.D., (See Attachment #13); Brenda and Tim Lancaster, (See Attachment #14); Darren Mosher, (See Attachment #15); Lisa Franklin, (See Attachment #16); Bill and Dorothy Fansler, (See Attachment #17; Jack Lee Cooper, (See Attachment #18); Ms. Suzette Garay, M.A., Pys.S., (See Attachment #19); David S. Rosenthal, (See Attachment #20); Leonard Hall, (See Attachment #21); Valarie L. Kerschen, M.D., (See Attachment #22); Lynn Eyrich, (See Attachment #23); Ann Curry, (See Attachment #24); Ellie Snelling, (See Attachment #25); Teresa L. Belt, (See Attachment #26); Richard Lutz, M.D., (See Attachment #27); Craig Kaberline, Kansas Council on Developmental Disabilities, (See Attachment #28); Glynis Murphy, PhD, CCC-A, (See Attachment #29); Larry E. Marston, University of Kansas, (See Attachment #30); Alicia Troike, Educational Audiologist, (See Attachment #31); Grace E. Kneil, (See Attachment #32);

The Chairperson closed the hearing on **HB 2362.**

The Chairperson opened the hearing on **HB 2314 -Lead Based Paint.**

Staff gave a briefing.

Sally Finney, Executive Director of the Kansas Public Health Association, testified in support of **HB 2314,** stating lead poisoning is one of the most pressing environmental problems facing children in the United States. The U.S. Agency for Toxic Substances and Disease Registry reports that one of every six children in the United States has high levels of lead in their blood. In 1994, the National Conference of State Legislatures released a report, "Lead Poisoning Prevention: A Guide for legislators." The following was cited: (1) Blood lead levels of less than 10 micrograms/deciliter may cause decreased IQ and impair hearing and growth. (2) Increasingly higher blood lead levels cause increasingly more severe complications ranging from a reduction in production of hemoglobin, the chemical that carries oxygen to cells, to nervous system damage. It may, in the most serious cases, cause kidney damage and death. (3) Children are more likely to be exposed to lead from exposure to lead-based paint than through any other source. (See Attachment #33)

Richard A. Baker, Co-Chair, Kansas Lead Council, testified as a proponent to **HB 2314**, stating this program would provide for the early detection of lead poisoning, before a child develops lead poisoning and suffers unnecessarily. This program would help Kansas citizens to identify lead hazards and remove those lead hazards before the disease has robbed our children of their intellect and happiness. The program would establish a statewide registry of persons who have been properly trained and who are professionally licensed to identify and remove lead hazards, which would create new jobs and also ensure the competency of those persons. The program would be able to identify the geographical areas of the state of Kansas where the greatest number of children have been lead poisoned (and where our children are at the greatest risk of lead poisoning). By having a statewide/state run program in place, the best interests of the citizens of the state would be decided by the state, rather than a federal agency whose only real impetus is to follow their congressional mandate. The state would also receive the value added benefit of being eligible to acquire literally millions of dollars in newly allocated funds from EPA, HUD, the Federal Centers for Disease Control and Prevention (CDC), as well as public and private foundations, which are specifically earmarked for lead poisoning prevention. (See Attachment #34)

Sam Umscheid, Wyandotte County Health Department, a proponent for **HB 2314,** stated there has been 133 cases in the county, 2 last month and for one child the bill at K.U. Medical Center was $176,000. (See Attachment #35)

Penny Selbee, R.N., supporting **HB 2314**, stated lead poisoning is one of the most common and preventable pediatric health problems today. Small amounts of lead, once thought to be harmless, can cause serious damage to our children without any evident symptoms. There are usually no symptoms unless a child is severely poisoned. Lead poisoning is widespread. No socioeconomic group, geographic area, or ethnic population is spared. Children ages 6 months to six years are the most vulnerable. Education is crucial to lead poisoning prevention. (See Attachment #36)

Barry Brooks, Kansas Childhood Lead Poisoning Prevention Program, KDHE, a proponent to **HB 2314** stated this issue was brought before legislature several years ago but in a different context. **HB 2314** provides the opportunity for the KDHE to address childhood lead poisoning as a public health issue, rather than an environmental abatement issue. The components of this bill address both the health of children and the environments they live in. The consequences of lead poisoning in children include adverse effects on learning, behavior and growth. High levels of lead poisoning can cause seizures, coma and death. The benefits of preventing lead poisoning include avoided medical and special education costs, increased lifetime earnings and reduces infant mortality.

HB 2314 also addresses issues related to training, worker certification, and work practice standards. This portion of this bill is directed at meeting the requirements of Section 402 of the Toxic Substances Control Act as required by the Residential lead-based Paint Hazard Reduction Act of 1992, administrated by EPA. This federal law requires certification programs for contractors to be in place by August 31, 1998. EPA would establish the program in Kansas if we do not. Federal grant funds are available for the states to establish such programs. (See Attachment #37)

Keith R. Landis, Committee on Publication for Kansas, Christian Science Committee on Publication for Kansas, requested an amendment to subsection 3 (a) (4) on page 2, lines 23-25 as follows: "(4) 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 grounds that such screening or testing is contrary to the parent's or guardian's religious beliefs and practices."* (See Attachment #38)

Testimony only was provided by Jolene Funk Registered Sanitarian, Environmental Supervisor, Saline County Health Department (See Attachment #39), Leadbusters, (See Attachment #40), Kansas State Nurses Association, (See Attachment #41), Doug Farquhar, NCSL, (See Attachment #42), Jane Campbell, (See Attachment #43).

The Chairperson closed the hearing on **HB 2314**.

The Chairperson stated that **HBs 2213 and 2261** would be worked on February 23.

The meeting adjourned at 3:15 p.m. The next meeting will be February 23.

Date: February 22, 1999

GUEST REGISTER

NAME	ORGANIZATION	ADDRESS
RICHARD A. BAKER	KANSAS LEAD COUNCIL	7941 WESTGATE STREET LENEXA, KS 66215
Barry Brooks	KS Dept of H & E	109 SW 9th Suite 604 Topeka KS 66612
Sally Finney	Ks. Public Health Assn	215 SE 8th Topeka, KS 66603
Kerrie Kuhlman	KS Nursing Home Administrators Assoc.	3601 SW 29th #202 Topeka, KS 66604
Kevin Kelley	KPNHAA	Topeka, KS 66604
Brenda Eddy	TAP	Topeka, KS
Carolyn Jeffries	TILRC	Topeka, KS
Kim Adams	TILRC	Topeka, KS
Jeffrey D. Brooks	Interpreter For the Deaf	Lawrence, Ks.
Bill Fansler	KCDHH & KS Assn of Deaf	TOPEKA, Ks
Grace E. Kneil	teacher of the deaf & parent	6110 Edinburg Wichita, KS 67220
KEITH R LANDIS	CHRISTIAN SCIENCE COMMITTEE ON PUBLICATION FOR KANSAS	TOPEKA
Lorna Alexander	Parent of Deaf Child 300 S. Cayuga	Frontenac 66763
Rebecca J. Aranda	KCDHH / White Lakes Mall 3640 SW Topeka Blvd. →	
Trisha Harrington	LINK, Inc.	2401 East 13th Hays, KS 67601

Date: 02/22/99

GUEST REGISTER

NAME	ORGANIZATION	ADDRESS
Roy T. Ortman	KDHE	400 SW 8th Street Suite 203 TOPEKA KS 66603-3930
Sue Bowden	KDHE	109 SW 9th St Suite 604 TOPEKA, KS 66612
SAM UMSCHEID	Wy Co Health	619 ANN KCKs 66101
Marty W Turner MD	KAFP - Doc of Day	2510 N Old Manor Wichita KS 67220
Teresa Kennalley	Via Christi Regional Med Center	929 N. St Francis Wichita Ks 67214
Stephen N. Paige	KDHE	Topeka
Meg Draper	KS Medical Society	Topeka
JANET STUBBS	KBIA	"
Carol McDowell	KPA	"
Cassie Lauver	KDHE	Topeka
Craig Kaberline	KS COUNCIL ON DD	TOPEKA
PENNY Selbee	citizen	5626 SW Hawick LN Topeka, Ks 66614
Dr Berk Gaughan	KCANNA Ear, Nose & throat Assn	12906 Goddard OP Ks 66213

February 22, 1999

Re: **HB 2362 -Newborn Infant Hearing Screening Act**

Dear Representative Boston, Chair, and members of the House Committee on Health and Human Services;

As an Deaf person, and Executive Director of the Kansas Commission of the Deaf and Hard of Hearing I am writing to express my support for newborn infant hearing screening act (*House Bill 2362*).

I have had a severe hearing loss since birth due to my mother having rubella during her first trimester. Because of my severe hearing loss I was able to hear certain sounds which made it difficult to identify and intervene. I would respond only to loud sounds but not speech, it was not until I reached the age of two years before I was identified. During the sixties a child being identified at age 2 years was considered "early" due to lacking technology and knowledge.

After I was identified with a severe to profound hearing loss it was apparent that I was behind two years in language and speech compared to a child with normal hearing. My parents had to work very hard and sacrificed a lot to assist me with language development. Today my language and speech is adequate, but I find writing English such a chore. I often need someone to edit my papers!

Thank goodness for today's technology; we can now identify infants at birth! *House Bill 2362* will ensure that all newborns are screened. Those with a moderate to severe hearing loss will be identified and appropriate intervention will follow so that children and parents do not experience delays in language development and education.

Please vote favorably for HB 2362 and work for its passage. Thank you for your time and consideration to this matter.

Sincerely,

Rebecca J. Aranda

Rebecca J. Aranda,

HHS
2-22-99
Atch #1

TESTIMONY IN SUPPORT OF HOUSE BILL NO. 2362
NEWBORN INFANT HEARING SCREENING ACT

Chairman, Representative Garry Boston, and Committee Members, my name is Dr. Rebecca Gaughan and I am here today to support House Bill No. 2362, the Newborn Infant Hearing Screening Act.

I am a practicing otolaryngologist - head and neck surgeon (ear, nose, and throat physician) in private practice in Olathe, Kansas for the past ten years. I have served as the otolaryngologist for the state on the Kansas Commission for the Deaf and Hard of Hearing for the past five years. I am actively involved in both the county and state medical societies.

I am here today because I have personally seen children whose hearing loss was first identified over the age of two. I have seen the devastating consequences. My partner just saw a 2 1/2 year old boy from Mound City, Kansas whose parents had no idea that he had a severe hearing loss. If this child had been screened at birth, he would not be behind in speech and language development today.

Currently, the State of Kansas performs a hearing screen on infants that meet the high risk category, as defined by our state. Unfortunately, not only in our state, but across the country, this only picks up 50% of the babies that actually have a hearing loss present at birth.

Approximately 1 of every 1000 children born in the United States is born deaf. In our state, as many as 900 infants a year suffer from undetected hearing loss.

New scientific evidence overwhelmingly shows that infants whose deafness is detected early, and certainly within the first six months after birth, can learn to communicate far better than those whose impairment is found later. Studies show that without hearing aids or some type of amplification by at least six months of age, certain brain pathways will close off. By the time children with hearing loss enter the first grade, children identified and treated before six months of age are one to two years ahead of their later identified peers in language, cognitive, and social skills. Infants with hearing loss can benefit from amplification (hearing aids) as young age four weeks of age. If hearing loss remains undetected, even a mild loss in one ear, studies have shown substantial detrimental consequences. For example, research shows that children with hearing loss in one ear are ten times as likely to be held back at least one grade, compared to a match group of children with two normal hearing ears.

Hearing loss is invisible. When a baby is born, his or her ears, nose, throat, lungs, heart, etc., are examined. Various tests are performed which do not detect hearing loss. Examination for hearing loss requires special technology that is not currently being used state wide.

HHS
2-22-99
Atch#2

Parents, although occasionally extremely observant, typically fail to adequately identify hearing loss in their own children before their first birthday. Even when subsequently proven to be correct, initial parental concerns are frequently discounted by well meaning physicians or other health professionals. Currently the average age of diagnosis for congenital hearing loss is 2 1/2 years of age for children not screened at birth.

We now have the technology to detect hearing loss at a reasonable cost in newborns. Various tests can be performed in the newborn nursery by nurses or other volunteers. Testing for infant hearing can be performed within five minutes. The tests can be easily repeated. The cost for equipment to detect hearing loss at birth is approximately is $7000.

The identification of congenital hearing loss is well recognized as an opportunity for effective screening and early treatment. The National Institute of Health has recommended that newborn hearing screening be implemented universally. The Joint Committee on Infant Hearing, representing the American Academy of Pediatrics, the American Academy of Otolaryngology, the American Academy of Audiology, and the American Speech and Language Hearing Association has similarly recommended hearing screening for all newborns.

I have addressed the problem that we are missing half the children in Kansas born deaf or hard of hearing and this problem can be easily detected with a quick screening test performed in the immediate newborn period. I would now like to address the cost.

In the state of Colorado, a study was undertaken between 1992 and 1996 in hospitals with 100 or more births per year to screen all newborns. Data from Colorado showed the true cost for each infant screen as estimated to be about $25.00 per infant, including labor costs, disposable supplies, and amortized capital equipment costs. By comparison, the true cost of a blood screening test for any of the known newborn genetic diseases is estimated to be about $3.00 per infant. You must, however, interpret this data in the context of a disorder that is by no means rare. In Colorado, the screening costs required to identify correctly one new case of congenital hearing loss are calculated to be $9600. Even though the cost per test is much less for each blood test performed, the newborn genetic diseases screened are much less common. The cost per case diagnosed, therefore, is similar..$10,000 per case for hypothyroidism, $20,000 per case for hemoglobinopathy, and $40,000 per case for PKU (phenylketonuria).

For the first 2 1/2 years of a Universal Screening Program, there is no savings expected to the state. However, beginning in the third year, true savings can be calculated in the avoidable cost of later evaluation and intensive speech/language intervention. If only half of children born with hearing loss realize some ultimate savings in school based costs because of newborn screening and early amplification, it is estimated that the Universal Screening Program in Colorado could recover all of the screening costs after only ten years.

Universal Newborn Infant Hearing Screening could, in the long run, actually save the state money. Research shows by the time a child with a hearing loss graduates from high school, as much as $421,000 per child can be saved in special education costs of the child is identified early and given appropriate early interventions. These savings to the state in special education will pay for Universal Newborn Hearing Screening Detection and Intervention many times over. Universal Newborn Infant Hearing Screening actually saves the state money in the long run.

Today K.U. Medical Center in Kansas City has a Universal Infant Hearing Screening Program. Universal Infant Hearing Screening has been performed in Wichita in the past. Currently Olathe Medical Center, where I practice, is developing a Universal Infant Hearing Screening Program. We are working with senior medical students from Kansas University School of Medicine in the Health of the Public Class. These students are working on developing an educational pamphlet for parents to understand hearing screening and its importance. They are working with us to develop a model community hospital program and manual at Olathe Medical Center that can be used in hospitals across the state. This program is designed so that an audiologist or an ear, nose, and throat specialist does not have to be on hand or even in the near vicinity to perform this test.

In closing, I want you to imagine that there exists a disorder that children are born with that can be detected at birth with today's technology, but on an average is not diagnosed until age 2 1/2 years, even by experienced physicians. Imagine that this same congenital condition can be treated with early intervention to prevent developmental delays and measurable cognitive deficits that affect school performance. Imagine that the cost to identify each new case is comparable with the cost of identifying one case of any of the commonly screened newborn genetic disorders in the state of Kansas. Imagine if the direct cost of this program will be recovered after only one decade by preventing delayed and therefore more intensive intervention. Finally, imagine that the incidence of this single, screenable, treatable newborn condition is many times higher than the incidence of PKU, hypothyroidism, or the other diseases we screen for in this state. This disorder is not imaginary. It is real. This disorder is congenital hearing loss and we are missing half the children in this state born with a hearing loss with our current screening methods.

Thank you for your time. I would be happy to answer any questions.

Appendix A.   Dr. Gaughan

Newborn Hearing Screening: The Great Omission

Albert L. Mehl, MD*‡, and Vickie Thomson, MA§

ABSTRACT. *Objective.* The advent of technologic improvements in assessing the hearing of newborn infants has made possible the implementation of universal newborn hearing screening. Furthermore, selective screening based on high-risk criteria fails to detect half of all infants with congenital hearing loss. Although universal screening has been recommended by the National Institutes of Health and the Joint Committee on Infant Hearing Screening, data to support this recommendation have been incomplete, and the recommendation has been seen as without solid foundation by many in the pediatrics field. This study was designed to assess the feasibility, accuracy, and cost-effectiveness of a hospital-based hearing screening program for all newborns.

Methodology. Between 1992 and 1996, hospitals in Colorado with 100 or more births per year were targeted to participate in universal hearing screening of newborns. To date, 26 of 52 targeted hospitals, ranging in size from 40 to 3500 births per year, have implemented universal screening. A total of 41 796 infants were screened between 1992 and 1996. Screening was performed using automated auditory brainstem response, otoacoustic emission testing, or conventional auditory brainstem response, with follow-up testing performed on those infants who failed initial screening.

Results. Of 41 796 infants screened at birth, 2709 failed initial screening, and of 1296 who have completed reevaluation, 94 have been identified with congenital sensorineural hearing loss (75 bilateral) and an additional 32 identified with conductive hearing loss (14 bilateral). The frequency of bilateral congenital hearing loss requiring amplification therefore is shown to be at least 1 in every 500 newborns. During the study period, an additional 17 children with significant hearing loss not identified until ≥18 months of age were reported voluntarily; all 17 had been born at hospitals not participating in newborn hearing screening.

The false-positive rate for the screening program to date in Colorado is calculated to be 6%, but evolving technology has resulted in improvements to as low as 2%. Positive predictive value of an abnormal screen result is shown to be at least 5%, and as high as 19%, with improving technology. The sensitivity of newborn screening is demonstrated to be at or near 100%. Costs of screening are compared with other screened congenital diseases; although the true cost per child for newborn hearing screening is significantly higher than screening tests performed on blood, the much higher incidence of congenital hearing loss results in a comparable cost per case diagnosed when compared with hypothyroidism or phenylketonuria, for example. The feasibility of early intervention is demonstrated, with amplification by the use of hearing aids being the catalyst for effective treatment.

Finally, the costs of screening and early intervention are compared with the monetary savings in avoiding delayed and therefore intensive therapy and intervention for children not diagnosed at birth. The true cost of screening for one newborn is shown to be between $18 and $33, with an average cost of $25 per infant. The cost per case of congenital hearing loss diagnosed is ~$9600. A model for cost predictions and subsequent intervention savings is presented, and recovery of all screening costs is demonstrated after only 10 years of universal screening in Colorado.

Conclusions. Universal newborn hearing screening is feasible, beneficial, and justified, as indicated by the frequency of the disease, the accuracy of screening tests, the ability to provide early intervention, the improved outcomes attributable to early amplification, and the recovery of all screening costs in the prevention of future intervention costs. Furthermore, the incidence of bilateral congenital hearing loss is alarming, and is, in fact, many times greater than the combined incidence of all newborn screening tests currently performed on blood samples. The demonstrated effectiveness of newborn hearing screening and the availability of early amplification and intervention support the expanding recommendation that every newborn be screened for congenital hearing loss. *Pediatrics* 1998;101(1). URL: http://www.pediatrics.org/cgi/content/full/101/1/e4; *newborn, congenital, sensorineural, hearing loss, deafness.*

ABBREVIATIONS. A-ABR, automated auditory brainstem response; OAE, evoked otoacoustic emission; ABR, auditory brainstem response.

The Committee on Genetics of the American Academy of Pediatrics recently published a comparison of newborn screening programs in the United States and its territories.[1] The list and the accompanying fact sheets about each disease, although comprehensive in addressing screening tests performed on blood, ignore today's greatest opportunity in newborn screening.

Imagine that there exists a congenital disorder that is detectable at birth with today's technology, but on average is not diagnosed until age 2½ years, even by experienced physicians; imagine that this same condition can be treated with early intervention to prevent developmental delays and measurable cognitive deficits; imagine that the cost to identify each new case is comparable with the cost of identifying

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From the *Colorado Newborn Hearing Screening Project, ‡State of Colorado Department of Health and Environment; and §Boulder Community Hospital, Boulder, Colorado.

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Reprint requests to (A.L.M.) Colorado Permanente Medical Group, 2525 13th St, Boulder, CO 80304.

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one case of any of the commonly screened newborn genetic disorders; imagine that a universal screening program for this disorder could recover all of its direct costs after only 1 decade by preventing delayed and intensive intervention; and finally, imagine that the incidence of this single screenable, treatable newborn condition is many times higher than the incidence of phenylketonuria, hypothyroidism, galactosemia, maple syrup urine disease, homocystinuria, biotinidase deficiency, cystic fibrosis, adrenal hyperplasia, tyrosinemia, toxoplasmosis, and hemoglobinopathy combined.

The disorder is not imaginary; it is real.

The disorder is congenital hearing loss.

Since 1992, voluntary hospital-based hearing screening of all newborns has been promoted in Colorado, with 26 of 52 targeted hospitals (≥100 births per year) participating through 1996, and nearly 60% of all newborns currently being screened. Legislation passed in 1997 will require more complete penetration of universal hearing screening programs in Colorado hospitals within the next 2 years. Rhode Island instituted legislation to screen all newborns beginning in 1992, and the states of Hawaii, Kentucky, Louisiana, New Mexico, and Wyoming have implemented statewide screening programs since that time. Ten additional states are participating in a Maternal and Child Health federally funded project to achieve universal screening by the year 2000.

For the past 5 years, the voluntary screening programs in the state of Colorado have been advancing the concept of screening every newborn for congenital hearing loss, through hospital-based testing by automated auditory brainstem response (A-ABR) and/or evoked otoacoustic emission (OAE) measurements. From this experience, we offer the following paper to complement the report of the Committee on Genetics as well as to answer the concerns raised about both the feasibility of and the rationale for advocating universal screening of all newborns.[2]

METHODS

Between 1992 and 1996, 26 Colorado hospitals initiated hospital-based screening programs for testing the hearing of all newborn infants. The newborn census of participating hospitals ranged from as low as 40 births per year to as many as 3500 births per year. Depending on staffing requirements and the technique of hearing screening performed, hearing screening was performed anywhere from 3 hours of age to ≥48 hours of age, but in all cases was performed before hospital discharge unless extenuating circumstances were present.

Of the 26 hospitals, 19 relied primarily on testing by A-ABR. Equipment for this testing was manufactured by Natus Medical Incorporated (San Carlos, CA) and included models Algo 1, Algo 1E, and Algo 2. Of these 19 hospitals, 1 used audiologists to perform screening, 4 used technicians, 9 used nurses, and the remaining 5 used trained volunteers to perform the screening. One Colorado hospital used OAE testing as their preferred method of newborn hearing screening, with trained nursing personnel performing the testing and interpreting the results, supported by subsequent review by a certified audiologist. Equipment for OAE testing was manufactured by Otodynamics, (Hatfield, Herts, United Kingdom), model number 1L088. The remaining 6 hospitals screened all newborns using conventional auditory brainstem response (ABR) testing performed by certified audiologists in lieu of purchasing additional screening equipment.

Hospitals reported all screening results to the Colorado State Newborn Hearing Screening Project, a division of the State o Colorado Department of Health and Environment. Monthly reports were collated to produce cumulative data for the state, and technical support was made available to hospitals as required. Furthermore, voluntary reporting of all identified childhood hearing loss was ongoing during the study period, and summary data were compiled of children diagnosed later in preschool years who may or may not have received newborn hearing screening.

Educational programs were provided for the medical staff at participating hospitals, and the agreement of pediatric and/or family practice departments was a prerequisite to initiating universal hearing screening. Parents of newborns at each of the participating hospitals were informed of the availability and recommendation for screening every newborn, but were also offered the choice of signing a waiver to specifically decline testing. Approximately 3% of families elected to decline screening.

RESULTS

Of 41 796 infants screened between 1992 and 1996 in Colorado, 2709 failed the initial hearing screening. Of 1296 who failed initial newborn screening and have completed diagnostic follow-up, 94 had confirmed sensorineural hearing loss. Of these 94 newborns, 19 had unilateral sensorineural hearing loss, and the remaining 75 had bilateral sensorineural hearing loss, with 7 of the latter group having profound hearing loss. Early intervention, typically including amplification, has been made available to these 75 hearing-impaired newborns within 3 to 6 months of life.

In addition, 32 newborns who failed initial newborn screening have been identified with conductive hearing loss. Of these, 13 infants had structural or ossicular malformations and are expected to be candidates for possible surgical interventions; typically, early amplification has been necessary while awaiting later surgical correction. The remaining 19 had persistent neonatal middle ear effusions, in some cases associated with disorders such as Down syndrome or cleft lip and cleft palate; early correction by surgical placement of tympanostomy tubes has been the rule for these infants. (Although early detection of these infants with retained middle ear fluid has been of great value in their medical management, diagnosis by skilled otoscopy could be expected early in life; therefore, this group has been excluded from the more detailed cost analysis of congenital hearing loss reported in this paper.) The incidence of the bilateral congenital hearing loss, therefore, is estimated to be at least 1 in 500 newborns. (The incidence may be significantly higher if the frequency of the condition is similar in the group of infants who have not completed reevaluation.)

DISCUSSION

Newborn hearing screening has been advocated and performed in the United States since the pioneer work of Marion Downs in 1964.[3] However, the time requirements, variable state of newborn arousal, and subjectiveness of behavioral measurements in the past have prevented practical widespread screening. Parents, although occasionally extremely observant, typically fail to adequately identify hearing impairment in their own children before the first birthday. Even when subsequently proven to be correct, initial parental concerns are frequently discounted by well-

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meaning physicians or other health professionals. Currently, the average age of diagnosis for congenital hearing loss is 2 ½ years of age for children not screened at birth, and no trend toward improvement has been observed in this group. Since the inception of the Colorado Newborn Hearing Screening Project, 17 children with hearing loss identified at ≥18 months of age have been reported voluntarily; of these, all were born at hospitals not participating in universal hearing screening.

The incidence of congenital hearing loss is shown from the Colorado experience to be alarmingly high, with bilateral hearing loss present in at least 1 of every 500 newborns. For comparison, the incidence of commonly screened newborn disorders would be galactosemia, 2 per 100 000 births; phenylketonuria, 10 per 100 000 births; hypothyroidism, 25 per 100 000 births; and bilateral sensorineural hearing loss, 200 per 100 000 births (Table 1).

Before the availability of automated techniques for screening, the use of traditional ABR was performed selectively in some hospitals, with a high-risk registry used as a tool for selecting those infants who would be tested. Although the implementation of high-risk guidelines has been extremely variable in the past, a thorough screening for high-risk categories would include assessment of each of the following areas: asphyxia, meningitis, congenital or perinatal infections, anatomic defects or stigmata, hyperbilirubinemia, family history of hearing loss, low birth weight, ototoxic medications, and neonatal illnesses requiring mechanical ventilation.[4] When Colorado infants with proven congenital hearing loss were reviewed retrospectively for any of these high risk criteria, 63 of 126 affected newborns, or 50%, were shown to have no risk factors, and therefore would have never received newborn hearing screening in the traditional model of screening only at-risk infants.

In place of standard ABR testing, two newer techniques for universal neonatal screening are currently available, and both methods were used in the various Colorado hospitals studied. A-ABR allows for computerized interpretation and pass–fail reporting. This computerization makes it possible to perform screening with personnel of variable backgrounds and training. In Colorado, ~80% of all newborn screening is, in fact, performed by volunteers, technicians, or nurses, rather than by audiologists. A-ABR is also the preferred test in a setting of early hospital discharge, because neither middle ear fluid nor ear canal debris, often still present in the first 12 to 24 hours of life, will adversely affect the result. A-ABR requires infants to be asleep or in a quiet state at the time of testing.

OAE is also considered an appropriate screening tool. Similarly performed on a sleeping or quiet newborn, the test is quick in producing a result and involves less cost for disposable items. Interpretation by an audiologist is required, however, making this technique less appealing for smaller hospitals. The test is not accurate when the middle ear has not yet been adequately aerated after birth or when debris remains in the ear canal.

TABLE 1. Summary of Selected Colorado Newborn Screening Programs: A Comparison of Existing Screening Programs and Proposed Universal Infant Hearing Screening

	Congenital Hearing Loss	Hypothyroidism	Phenylketonuria	Cystic Fibrosis	Hemoglobinopathy
Frequency per 100 000 births	260 (200 Bilateral)	25	7	50	13
Yearly Colorado births	54 000	54 000	54 000	54 000	54 000
Number positive, first screen	3500 (1620 Expected)	600	5	600	600
Number of children diagnosed	140 (110 Bilateral)	15	4	27	7
Positive predictive value	5% (19% Expected)	3%	80%	4%	1%
Average age of diagnosis if unscreened	30 months	3–12 Months	3–12 Months	42 Months	3–36 Months
Cost of initial screen per child	$25	$3	$3	$3	$3
Screening cost per confirmed diagnosis	$9600 ($12 300 Bilateral)	$10 800	$40 500	$6000	$23 100
Effectiveness of treatment	2+	3+	3+	1+	2+
Clinical result of delayed diagnosis	Language delay, academic delay, psychosocial difficulties, cognitive delays	Lethargy, confusion, poor memory, myxedema, coma, cretinism	Seizures, tremors, severe irreversible mental retardation	Malnutrition	Bacterial sepsis, anemia, sickling crisis

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In addition, the two tests have been combined in some centers, effectively creating a two-stage screening process while infants are still in the hospital. To achieve effective universal screening, initial screening tests are best performed before newborn discharge from the hospital; screening tests performed after hospital discharge can be influenced negatively by the failure of families to return for retesting and by the failure of newborns to be in a quiet state at their appointed time for rescreening.

Newborns who fail initial screening must return for adequate follow-up testing, and appropriate systems need to be in place to ensure timely recall. Although a number of Colorado newborns who failed initial screening have follow-up evaluation in progress, there is clearly an opportunity for improvement in ensuring retesting of all newborns who fail the initial screening. Initial follow-up testing typically includes a rescreening by one or more of the techniques described above. Infants who fail this second screening require a comprehensive audiology evaluation.

Of 41 796 newborns screened to date in Colorado, no evidence of even a single false-negative test result has been discovered; the sensitivity of newborn screening is therefore at or near 100%. Since the inception of newborn hearing screening in Colorado, the cumulative false-positive rate is ~6%. With improving technology, a trend toward greater specificity is noted; specifically, the second generation of A-ABR equipment currently used widely in Colorado (Algo 2, Natus Medical Inc) has allowed for a false-positive rate as low as 2%.

Even this lower rate of 2%, when compared with other commonly screened newborn disorders, may appear to be higher than desirable. It is important, however, to interpret this rate carefully in the context of a disease that is many times more common than other conditions screened. A more meaningful number, therefore, is the positive predictive value of the test, namely the number of true positive results divided by the total number of positive screening tests. The positive predictive value for all newborn hearing screening to date in Colorado is ≥5%; calculated for second-generation A-ABR equipment only, the positive predictive value is now as high as 19%. This compares favorably in Colorado with the positive predictive values for hemoglobinopathy screening (1%), cystic fibrosis screening (4%), and hypothyroidism screening (3%). In fact, the positive predictive value for newborn hearing screening is exceeded in Colorado only by screening for phenylketonuria (80%) (Table 1).

Unilateral congenital hearing loss is, admittedly, a relatively minor disability in language and cognitive development. It is, nevertheless, an educational disability that is managed easily, but only after adequate and, preferably, early diagnosis.

Bilateral congenital hearing loss, however, is of greater significance. On average, language delay at the time of diagnosis ranges from 12 months to ≥2 years. Treatment after diagnosis, typically after age 2, requires intensive therapy for both articulation and expressive–receptive language development. Even years of intensive intervention will fall short of achieving results comparable with language development in children with normal hearing.

With neonatal screening and early diagnostic confirmation, amplification and intervention can be initiated within the first 3 months of life. Because only 10% of affected newborns have profound hearing loss (7 of 75 newborns with bilateral sensorineural hearing loss identified to date in Colorado), major improvements in outcome can be obtained with amplification, careful audiology follow-up, and appropriate habilitation. With early amplification and appropriate therapy, children who are hearing-impaired are capable of achieving normal speech–language developmental milestones. Yoshinaga-Itano and coworkers have shown that a cohort of affected newborns identified through newborn screening achieved near-normal language development, significantly exceeding the language development of comparable children not identified until after 6 months of age.[5]

Early consistent amplification is the catalyst for effective intervention for newborns with sensorineural hearing loss as well as for infants with conductive hearing loss awaiting later surgical intervention. Even though the 10% of hearing-impaired newborns with profound hearing loss receive limited benefit from traditional amplification, newer technologies may be introduced to facilitate communication development and to offer families a range of options for their child's education. In addition, surgical innovations such as cochlear implants are increasingly available. In the case of profound hearing loss, use of sign language may be initiated in early infancy to facilitate communication.

For all infants affected, management by a certified audiologist is necessary, in conjunction with a primary care physician invested in coordinating adequate follow-up. Evaluation by a language specialist is essential, although some amplified infants require only limited formal therapy. Individual detection of newborns affected, combined with family history and additional medical evaluation when indicated, also allows for genetic counseling and recurrence risk estimation when appropriate.

It is important to note that a normal screening test does not preclude the subsequent diagnosis of an acquired sensorineural hearing loss (secondary to meningitis, for example), nor does it preclude a progressive hearing loss with onset later in childhood. Furthermore, the possibility of subsequently acquired conductive hearing loss (from chronic middle ear effusion, for example) will, of course, require the clinician to continue a vigilant approach to assessment of hearing acuity and language development, even when newborn screening has been documented as normal.

Screening for congenital hearing loss is clearly a significant undertaking. Because this screening does not involve a blood test, the costs are independent of structures already in place to support universal blood screening tests. The true cost for each infant screened is estimated to be $25 per infant, including labor costs, disposable supplies, and amortized cap-

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TABLE 2. Cost Analysis of Proposed Universal Newborn Hearing Screening in Colorado

Year	Yearly Costs			Cumulative Costs/Savings			
	Initial Screen Costs	Confirmatory Evaluation Costs	Cost of Intervention	Cumulative Cost	Cumulative Eval and Therapy Savings	Cumulative Education Savings	Net Cost or (Savings)
1	1.45	0.2	0.07	1.72	0	0	1.72
2	1.45	0.2	0.20	3.56	0	0	3.56
3	1.45	0.2	0.26	5.47	0.10	0	5.37
4	1.45	0.2	0.26	7.38	0.79	0.14	6.46
5	1.45	0.2	0.26	9.29	2.13	0.61	6.55
6	1.45	0.2	0.26	11.2	4.04	1.32	5.84
7	1.45	0.2	0.26	13.1	6.03	2.25	4.82
8	1.45	0.2	0.26	15.0	8.01	3.41	3.58
9	1.45	0.2	0.26	16.9	10.0	4.81	2.09
10	1.45	0.2	0.26	18.8	12.0	6.43	0.37
11	1.45	0.2	0.26	20.7	14.0	8.27	(1.57)
12	1.45	0.2	0.26	22.6	16.0	10.4	(3.80)

Figures shown in millions of dollars. All figures in 1996 dollars.

Notes: Calculations based on the following assumptions:

All cost figures reflect estimated true costs, not charges.

54 000 births per year, every year.

Frequency of congenital bilateral hearing loss 2 per 1000 newborns

Cost per initial screening, $25 per infant; cost of follow-up program and coordinator, estimated at $100 000 per year included in initial screening costs.

Cost of confirmatory evaluation, $125 per infant who fails initial screening, unilateral or bilateral; costs based on a refer rate of 3.0% of all newborns failing initial screening.

Cost of intervention associated with amplification $1200 per year for 2 years in follow-up costs. The cost of the amplification device, required both for infants with early diagnosis and with late diagnosis, has been excluded from calculations.

Age of diagnosis if not screened at birth assumed to be 30 months.

Cost of confirmatory late diagnosis estimated to be $400 per affected child, for behavioral testing and brainstem auditory evoked response with sedation.

Cost of therapy savings estimated at $40 true cost per session, 3 days per week, 50 weeks per year, for 3 years, for each child with prevention of delayed diagnosis of bilateral sensorineural hearing loss; zero therapy savings estimated if unilateral.

Cost of preschool educational savings estimated as follows: assuming that half of children with delayed diagnosis would require 1 year of early intervention preschool home program ($2600 per year), followed by 1 year of specialized preschool ($6200 per year), avoidable if diagnosed at birth.

Cost of school-age educational savings estimated as follows: Assuming delayed diagnosis results in 13% residential placement (cost exceeding standard education by $25 000 per year), 23% self-contained classroom ($8300 per year excess costs), 28% resource programs ($2300 per year excess costs), and 34% consultative/itinerant programs ($700 per year excess costs), and assuming that identification at birth would allow for a one-level shift to less-intensive educational setting for only half of each cohort as they enter the educational system, for the first year and each subsequent year; finally, assuming all educational savings apply only to prevention of delayed diagnosis of bilateral sensorineural hearing loss, with zero educational savings for treatment of unilateral hearing loss. (Costs and percentages: Colorado Department of Education, 1993 data.)

Model assumes that infants identified with congenital sensorineural hearing loss do not move out of Colorado during the 10-year period.

Negative net costs shown in parentheses are the equivalent of net savings.

ital equipment costs. (To date in Colorado, the costs of screening range from $18.30 per infant when performed by supervised volunteers, to $ 25.60 per infant when performed by a paid technician, and to $33.30 per infant when performed by an audiologist. Improving technology with improved speed of testing is noted to have decreased these estimates in 1997.) By comparison, the true cost of a blood screening test, including laboratory, phlebotomy, and personnel costs, for any one of the newborn genetic screen diseases in Colorado is estimated to be $3 per infant (Table 1). (Hospital and/or laboratory billed charges for both hearing screening and blood screening can be expected, of course, to exceed these estimates of true cost.)

The cost of screening for congenital sensorineural hearing loss, however, must again be interpreted in the context of a disorder that is by no means rare. In Colorado, the screening costs required to identify correctly one new case of congenital hearing loss are calculated to be $9600. Even though the cost per test is much less for each blood test performed, the newborn genetic screen diseases are much less common. The cost per case diagnosed, therefore, is similar: $10 000 per case for hypothyroidism, $23 000 per case for hemoglobinopathy, and $40 000 per case for phenylketonuria (Table 1). Finally, the labor costs of using the traditional high-risk registry followed by selective screening to identify children with hearing loss can be expected to approach the labor costs of universal screening. However, a thorough application of this traditional high-risk method would fail to detect 50% of newborns affected.

In 1997, the state of Colorado has legislated a requirement for more complete penetration of universal newborn hearing screening among the state's hospitals; the total estimated cost to screen every one of Colorado's 54 000 births each year, followed by confirmatory testing for those who failed the initial screen, would be $1 650 000. Follow-up associated with amplification of infants affected would require another $260 000 per year on average. For the first 2 ½ years, no savings would be expected from a universal screening program, because unscreened hear-

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ng-impaired children are diagnosed, on average, some 30 months later. Nevertheless, beginning in the 3rd year, true savings can be calculated in the avoidable costs of later evaluation and intensive speech–language intervention. Without screening, such intervention is required in hope of achieving an imperfect recovery of language development and cognitive losses. Furthermore, additional expenses accrue for children not diagnosed at birth who go on to require some form of special intervention once they reach school age, ranging from itinerant and resource programs, to self-contained classrooms, to residential placement. If only half of hearing-impaired children realized some ultimate savings in school-based costs because of newborn screening and early amplification, a universal screening program in Colorado could recover all screening costs after only 10 years through subsequent savings in avoided intervention (Table 2). Recovery of all initial costs (and subsequent cost savings) is independent of improved developmental outcomes, a worthy goal in and of itself.

Identification of congenital hearing loss is well recognized as an opportunity for effective screening and early treatment. National Institutes of Health has recommended that newborn hearing screening be implemented universally.[6] The Joint Committee on Infant Hearing, representing the American Academy of Pediatrics, the American Academy of Otolaryngology, the American Academy of Audiology, and the American Speech–Language–Hearing Association, has similarly recommended hearing screening for all newborns.[7]

The pediatrics community as a whole, however, is only beginning to realize the potential of new technology in diagnosing this disorder accurately in a newborn baby. Congenital hearing loss is far too common, and the developmental disabilities far too devastating and expensive to allow the initial costs to be a barrier to pursuing this exciting initiative. The Newborn Hearing Screening Project of the State of Colorado encourages all neonatologists, pediatricians, and family practitioners to include newborn hearing screening as a necessary and effective test for every newborn.

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2-9

Testimony on HB 2362
Rep. Garry G. Boston, Chairperson
Committee on Health and Human Services
February 22, 1999

Dear Chairman Rep. Garry G. Boston and committee members:

Thank you for the opportunity I have today to give a statement on HB 2362.

My name is Trisha Harrington. I live and work in Hays, Ks. I have been profoundly deaf since birth. I am also a professional in the business of providing services to people who are deaf and hard of hearing as well as other disabilities. I am employed at LINK, Inc. and also work with Kansas Rehabilitation Services.

I would like to give a statement of my opinion in regards to HB 2362. I believe it is of utmost importance to mandate testing of newborn babies in the state of Kansas for potential hearing deficits. I am well aware that early identification is a key to successful education of deaf and hard of hearing children. Parents must decide how best to approach their children's education upon learning that their child has a hearing loss. The earlier hearing loss is identified, parents can spend the early months of the child's life assessing whether manual, oral/auditory, or total communications is best for the child. All three options of education and communications are outstanding and successful if started early. If children are not tested at birth, great difficulty in the development of language, social/peer success, and low self esteem is likely. It is common and frustrating for both parents and child to face the battles which lay ahead when a child can not communicate with family and peers and understand the happenings of the environment which they live in. There is research which indicates the validity of the facts I have just stated.

It is unfortunate my hearing loss was not discovered until I was 6 months old. My parents took action after much information gathering and placed me in the educational approach of their choice at the age of 9 months. I am convinced that early identification helped me to be the person I am today. The children are our future. Let's work together to ensure the best possible start for all children.

HHS
2-23-99
Atch#3

Please consider passage of this bill and help parents make informed decisions to ensure the best possible start in life.

Thank you for your time.

Trisha Harrington
2401 East 13th
Hays, KS 67601
785-625-6942 TTY/v

February 19, 1999

Dear Chairman Rep. Garry G. Boston and Committee Members:

Hearing loss is present in 3 of every 1,000 births, making it the most frequently occurring birth defect. Early detection of this hearing loss is critical for early intervention and support to be given to the infant and to the family.

When children are not identified early, it is difficult for them to acquire the fundamental language, social, and cognitive skills that provide the basic foundation for school success and later success in society.

On the other hand when there is early detection and intervention the child makes dramatic process, they become more successful in school, and become more productive members of society.

As a professional who works with these children everyday, and teach sign classes for parents of deaf children, I see such a vast difference in the child that was identified early. These children have language and communication skills taught from infancy, instead of those identified at 2 or 3 years of age. The 2 or 3 year old child is full of frustration, they are delayed in language and cognitive skills, and lack even the basic social skill. Families are frustrated and many times angry and confused as to what to do with this child. So many times we see aggressive behavior, as a result of not being able to communicate the simplest need or want.

We want to give each child that is born an opportunity to be able to achieve any goal in life they set. We want to give them every advantage to become successful and meaningful participants of society. Not just spectators, but active, involved, productive children and adults. Early intervention with children that have a hearing loss helps to make that possible. Please support House Bill No. 2362, "Kansas Infant Hearing Screening", and make a difference in the lives of these children and their families.

Cheryl Jackson
Sign Language Interpreter
Speech and Language Tech.
SEK Education Service Center
Deaf Education Program

HHS
2-22-99
Atch#4

22 February 99

To: Representative Garry G. Boston, Chair
Members of the House Committee on Health and Human Services

House Bill 2362 - Newborn Infant Hearing Screening Act

Dear Representative Boston and Committee Members

I am the parent of a profoundly deaf child who was identified at 10 months of age. Gina is currently a second grader who attends a public school receiving the bulk of her instruction in a regular 2nd grade classrom with the assistance of an interpreter. She is in the top reading group in her grade and is performing at the top of her class in all areas of instruction. She participates in many activities in her community. She plays t-ball and basketball, is on a bowling league, takes dance lessons, and goes to the youth program in our church.

Due to my occupation as a special education administrator, working with audiologists and teachers of the deaf, I was more educated in the importance of early diagnosis and education of deaf children. When we had some question as to our daughter's hearing at 10 months, she was evaluated and identified as having a profound bilateral loss. She was fit with hearing aids at 11 months, and began home programming in our home, in her daycare and in her grandparents home. She had an early childhood special education teacher who was a fluent signer from the age of 16 months until her placement in a deaf education preschool at 3 years of age. And she had a family who signed to her. These things took place because she had parents who were in the right place (or profession) at the right time.

I credit early identification and intervention as the cause of Gina's academic success. Unfortunately, we see too many children who aren't identified until two and three years of age. Much of the valuable early language acquisition time has passed them by. With the mandatory screening of newborn infants in the hospital, we will be assured of finding children with hearing loss, and we will give all of our Kansas children the chance to have the same benefits and programming that has made our little girl excel. I ask for your full support of Kansas House Bill 2362 to enact the Newborn Infant Hearing Screening Act.

Sincerely

Lorna Alexander

Lorna Alexander
parent

HHS
2-22-99
Atch#5

Technology
For
Kansans

Parsons, KS
67357

316-421-8367
(V/TTY)

316-421-0954
(FAX)

Coordinated by the
University of Kansas
At Parsons

Information and
Referral Phone
800-526-3648
(Voice)
800-500-1034
(TTY)

Memo To: House Committee on Health and Human Services

From: Sara Sack, Ph.D., Co- Director of the Assistive Technology for Kansans Project

RE: HB-2362--Universal Newborn Hearing Screening

I am writing from both my personal and professional experience to support implementation of newborn hearing screening in Kansas. Within my own family, my sister-in-law was 23 months old before her profound hearing loss was diagnosed. Valuable learning time was lost because Laurel did not have much needed hearing aids. In my professional life as a speech-language clinician, I frequently work with young children who have undiagnosed hearing loss. Being unaided during the language learning years negatively impacts language learning. And finally, as Co-Director of the Assistive Technology for Kansans Project, a network of consumers, service providers, and organizations who support individuals in acquiring and learning to use assistive technology devices, such as assistive listening devices and hearing aids, I am aware that children's hearing loss could be detected at an earlier age.

There is clear evidence that universal newborn hearing screening substantially lowers the age at which children with congenital permanent hearing loss are identified. Children who are identified early and receive intensive early intervention perform significantly higher on school-related tests than children who do not receive such intervention. The current average age for detecting significant hearing loss in children is 14 months.

Passage of H.B. 2362 will help children who have hearing loss have the support that they need to make the most of the language learning years. The Assistive Technology for Kansans Project supports the passage of this legislation and will work with children, families, and service providers to see that Kansans have the assistive technology devices and services they need.

Sincerely,

Sara Sack

Sara Sack, Ph. D., CCC-SLP
Co-Director of Assistive Technology for Kansans Project

HHS
2-22-99
Atch# 6

The University of Kansas

Schiefelbusch Institute for Life Span Studies
Parsons Research Center

February 19, 1999

Re: HB 2362

Dear Representative Boston, Chair, and members of the House Committe on Health and Human Services,

I am writing in support of House Bill 2362 for Kansas newborn hearing screening. Much of my 30 year career has been spent in research and training in the area of early identification of hearing and vision problems. Without question, the impact of early identification of such problems is immense, allowing the child to develop the necessary communication and cognitive skills to reach his or her full potential. Conversely, children whose sensory impairments are not identified until later in life may be permanently and adversely affected by the loss of sensory input at the critical stage of early development.

For some time we have had the technology to screen for hearing problems in very young children. The implementation of a statewide screening program would finally put that technology to work to improve the lives of young Kansans with hearing impairments. This initiative would be an excellent, cost-effective investment in our most precious resource, coming generations of Kansans. Please give your whole-hearted support to this bill.

Sincerely,

Pamela Cress

Pamela Cress
Program Coordinator
University of Kansas Affiliated Program at Parsons

2601 Gabriel • Parsons, KS 67357 • (316) 421-6550 Ext. 1898 • (316) 421-8367 (V/TTY) • Fax: (316) 421-0954
prc@parsons.lsi.ukans.edu

HHS
2-22-99
Atch #7

7

February 19, 1999

Dear Chairman Rep. Garry G Boston and Committee Members:

Early identification of hearing loss is essential to assist the individual in developing his or her full potential. I make this statement as a Speech Language Pathologist who has worked with communicatively involved children for over 25 years. New advances in hearing loss identification now enable us to identify early, and to begin communication intervention early. Early intervention helps not only the identified individual, but the community as a whole by enhancing independence capabilities and earning power of the one identified.

I fully support the bill, and hope you and your committee will do likewise.

Obstacles are things a person sees when he takes his eyes off his goal.

Glenda Hurter,
Speech Pathologist, Myofunctional Therapist

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HHS
2-22-99
Atch#8

February 19, 1999

Dear Representative Garry G. Boston:

I wrote to you earlier today in favor of HB 2362. Please accept my apology concerning my error in your name and place of work. I received a phone call today to write to a Representative Garry from Boston. (smile) I assumed you were in Washington, D.C. I am quite pleased to find out you are working for the great state of Kansas! Good luck with the Universal Hearing Screening.

Sincerely,

Eileen Patterson

Eileen Patterson
12819 S. Navaho Dr.
Olathe, KS 66062
(913) 393-0278
FAX (913) 764-4138

HHS
2-22-99
Atch#9

February 19, 1999

Dear Chairman Rep. Garry G. Boston and Committee Members:

My son Chandler is lucky. He was born with a hearing loss. Looking at him you would never suspect that there was a problem. Fortunately, the hospital he was born in tests the hearing of **all** newborn babies. Chandler has worn hearing aids since he was 6 months old. He laughs, babbles and is learning to use sign language. Having found out about his hearing loss early gave us the opportunity to be prepared to help him, rather than waiting until there was a problem. Please support House Bill 2362 (Universal Hearing Screening) so that all deaf children can be as fortunate.

Sincerely,

Clysta Beal
Ft. Scott, Kansas

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HHS
2-22-99
Atch #10

February 19, 1999

Dear Chairman Rep. Garry G. Boston and Committee Members:

My name is Lori Burns, and I have a five year old son named John. John was born with cleft lip and palate, and, we have found out through time and experience, that he also has a severe hearing loss in his right ear. Along with all this, we have recently found out, he has a mild form of autism as well.

I am writing in hopes that one day there will be adequate testing for infants who are suspected to have any kind of hearing impairment. My son had, and continues to have, problems because of his hearing loss. John's speech is that of a toddler, maybe for a toddler around the age of two or so. His vocabulary consists of 20 or so words. He is getting better, but he struggles every day with his speech impairment. He goes to a special preschool, Harvey County Special Ed. Coop here in Newton, KS. They are helping him as much as they can. We try to work with him as much as possible, but I feel like any parent, there is always more you can do.

I hope in the near future, there will be testing done for every infant who anyone believes to have an impairment of any kind. I have been told time is of the essence. Any help given as soon as possible, is good help, am I correct??? I believe I am. I hope this letter gets in the right hands where it can do the most good. I do not wish there to be any needless time wasted on things such as, do the parents have enough money for testing?, do we really feel a child should be tested for a major impairment?

I was very surprised to hear that insurance does not cover hearing aids, and some don't even cover eyeglasses. I thought it was very important to see and hear, but apparently, some do not share my beliefs. If one does not hear, it could cause damage, in the worst case, death. I do not mean to preach, but I feel strongly about this subject. I worry my son could have been diagnosed earlier, and therefore, could have been helped sooner, so he could be more adapted with life than he is now.

Thank you for any time and consideration you give me and my son.

Sincerely,

Lori L. Burns
1221 Manchester
Newton, KS 67114
316-282-0560

HHS
2-22-99
Atch #11

Southeast Kansas
Education
Service Center

947 W. 57 HWY.
Girard, Ks. 66743-2347
316-724-6281 Fax 316-724-6284

19 February 1999

To: Representative Garry Boston, Chair
Members of the House Committee on Health and Human Services

Re: House Bill 2362 - Newborn Infant Hearing Screening Act

Dear Rep Boston and Committee Members

As an educational audiologist in Southeast Kansas, I have the opportunity to be involved with hearing impaired infants and toddlers, from the time they are first identified, until they graduate from high school. We are fortunate to have a hearing impaired program at our center, staffed with teachers of the hearing impaired, interpreters and audiologists. The earlier a child is identified with hearing impairment, the more successful their educational experience will be.

I ask for your full support of Kansas House Bill 2362 to enact the Newborn Infant Hearing Screening Act.

Sincerely

Heidi Daley, MS, CCC/A
Educational Audiologist

HHS
2-22-99
Atch# 12

12

February 19, 1999

Dear Chairman Boston and Committee Members:

The Kansas Infant Hearing Screening Program currently screens all newborns for conditions that put them at risk for hearing loss and if an infant is at risk, then hearing testing is recommended. When this law was enacted in 1991, it was believed to be adequate. Now we know that half of all congenital hearing loss will be missed if only at-risk infants are screened.

The more compelling argument for screening all newborns for hearing loss, however, is recent data from a superbly-done study in Colorado that shows that if intervention is begun before 6 months of age, children with hearing loss will develop language skills commensurate with normally-hearing infants! These findings apply to hearing loss of mild, moderate and severe degrees! It appears that infants who receive this very early language stimulation (either spoken language through hearing aids or sign language) learn language effortlessly. But, when intervention is delayed beyond 6 months, then language learning must be laboriously taught.

Clearly the long term savings from early detection and intervention are apparent: children and their families will have healthy communication and long-range special education costs should be reduced dramatically.

Please support House Bill 2362, so that Kansas infants with hearing loss can begin intervention within the first months of life.

Judith E. Widen, Ph.D.
Associate Professor
Department of Hearing and Speech
University of Kansas Medical Center

HHS
2-22-99
Atch# 13

February 19, 1999

Dear Chairman Representative Garry G. Boston & Committee Members:

We are the parents of two hearing impaired children. We have no family history of hearing loss, so the diagnosis of our son Tate, at age 2 years 8 months, was devastating. We soon learned that our son's language skills were at the 12 month old level. Tate received hearing aids and went through months of intensive speech therapy. He is close to age appropriate as far as receptive speech - understanding what he hears - but most likely will have some ongoing speech problems.

We were expecting our second child when Tate was diagnosed. Due to our "new" family history, Hope was diagnosed at two days. She received hearing aids at six weeks. The difference between Tate and Hope is amazing! Hope is age appropriate in both her receptive and expressive speech. Her communication skills at 15 months far exceed Tate's at the time he was diagnosed. At this point, it is doubtful Hope will need much intervention other than routine speech therapy available through the public school system.

The majority of language comprehension skills are developed by age three. We almost missed that window on Tate. Unfortunately, it appears Tate's hearing is getting worse. It is likely that Hope's hearing will follow the same pattern. In the worst case scenario they will lose all their hearing. There are devices available to help them, but Tate will struggle with speech. Hope is at a great advantage since she has had "normal" aided hearing most of her life.

Since Tate was our first child, we always referred to him as our "experimental child" - we had no idea what to expect. I am sure most first time parents feel the same way. This is probably the reason most hearing impaired children are not diagnosed until 2 1/2 - when the window for language development is quickly closing. Since we had no family history of hearing loss, we did not request a hearing screening at the time of Tate's birth. It is frustrating to us that a simple inexpensive test could have made our son's life so much easier.

Please support House Bill 2362. It will make a difference in people's lives.

Sincerely,

Brenda and Tim Lancaster
4042 Cranberry
Wichita, KS 67226

HHS
2-22-99
Atch #14

14

February 19, 1999

Dear Chairman Rep. Garry G. Boston and Committee Members:

We need to have this legislation passed to help the new parents learn about their infant. I can speak from experience. Our daughter who is 2 1/2 now was born deaf. We did not find out she was deaf until she was approximately 14 months old. This is too late to find out about the hearing of your child.

An ABR test will benefit everyone right after the baby is born. The earlier you can intervene and know there is a problem, the more research and help you can receive from others who have gone down the road. Please support the bill for universal screening of hearing.

Darren Mosher
1843 E. 152nd St
Olathe, KS 66062

HHS
2-22-99
Atch #15

15

February 1999

Dear Chairman Rep. Garry G. Boston and Committee Members:

You would never let a newborn leave the hospital with some questions on whether or not it was going to make it with adequate care and love. Why would you stifle a baby and hold it back by letting it go unnoticed whether it could hear or not? Children left until 2 or 3 years. of age undetected are then behind because they are missing out on a very big part of life--the ability to hear.

Why would you stifle our future?

Please support House bill #2362 Kansas Infant Hearing Screening.

Lisa Franklin
Mother of a deaf child

HHS
2-22-99
Atch#16

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Bill and Dorothy Fansler
1940 SW Bowman Court
Topeka, Kansas 66604-3315

1-800-766-3777 Kansas Message Relay 785-273-0612
785-273-9063 FAX
fanslerbd@cjnetworks.com e-mail

Re: HB No. 2362
Newborn Infant Hearing Screening Act

Dear Chairman Garry G. Boston
Committee Members:

I strongly believe that the screening act be enacted by this Legislature because it will benefit all newborn babies and their parents.

Early detection of hearing loss in infants is very important because of language development whether be it thru hearing or thru visualizing. If a baby is found to be hard or hearing or deaf, the parents can get proper information and advise from qualified personnel.

It is absolutely important for ALL infant develop spoken language AND sign language (if the baby is found to be deaf) at an early age. Everybody knows that a baby picks up spoken language thru hearing. More importantly, deaf babies can benefit greatly thru visualizing.

If a child receives proper communication, he/she will grow up to be an intelligent person and contribute greatly to society.

I have lots of experience in socializing with deaf and hard of hearing people. I know that many of them would have better jobs and lives only if they were detected as having hearing problems during the 1940s thru 1970s. Deaf children at these times did not develop any language before enrolling at a school for the deaf because their parents did not know anything about deafness and education for them.

My wife, Dorothy who became totally deaf thru spinal meningitis at 9 years old and I would appreciate if the Health and Human Services committee pass this bill as favorable to the House and eventually the Legislature.

Submitted by Bill Fansler
Bill Fansler 2-19-1999

HHS
2-22-99
Atch#17

February 19, 1999

Kansas House Bill No. 2362

Dear Chairman Rep. Garry. G. Boston and Committee Members:

On behalf of Kansas Association of the Deaf (KAD) and entire Deaf Communities in the State of Kansas, I am supporting House Bill No. 2362 of early infant hearing screening. It is mandatory process to have early intervention program bill being passed to become more efforts with these children who are in need of service.

Thank you for your consideration to make House Bill 2362 become a reality.

Sincerely,

Jack Lee Cooper, President
Kansas Association of the Deaf, Inc.

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HHS
2-22-99
Atch #18

February 19, 1999

Dear Chairman Rep. Garry G. Boston and Committee Members:

As a Deaf educator, former Parent & Infant Specialist, I am writing to express my support of the early infant screening bill [House Bill 2362]. In my 12 years of working directly with parents and their deaf children, the importance of early identification of hearing loss has long been recognized and has been the foundation for early intervention programs.

Many of these families begin with unclear expectations and a narrow focus of what a hearing loss entails for the future of their child. By providing a mandatory screening process for detecting hearing loss earlier in the child's life, I believe will evolve into better services that will produce a positive change in the lives of these children and their families. On a larger scale, the increasingly positive outcomes engendered by early intervention programs have occurred because of the growing sophistication of identifying these children early who are at risk. Therefore, by passing such a bill to make early infant screening a mandatory process will, in turn, enhance future intervention efforts with these children who are in need of services.

Sincerely,

Ms. Suzette Garay, M.A., Pys.S

HHS
2-22-99
Atch#19

19

22 February 1999

Chairman Garry G. Boston and Committee Members,
Committee on Health and Human Services
Kansas House of Representatives

Thank you for allowing my testimony supporting House Bill 2362, which is the Newborn Infant Hearing Screening Act. I am a product of early identification, having been identified as being Deaf almost immediately after birth back in 1950.

We have come a long way in improving the quality of life for Deaf people in the last 49 years, and yet, we have not done much. Today, education of Deaf children is not where it should be compared to the hearing students. Although progress continues to be made in the education of Deaf children, one constant factor among successful Deaf students is that they were identified almost immediately after birth. If deafness is identified within a few weeks after birth, the parents are then educated, resulting in quicker language intervention. The sooner language is taught, the greater the Deaf child's chances of academic success at least equal to or better than their hearing peers. The better the education and skills the Deaf child learns the better the job, income level, and quality of life he/she will enjoy. This translates to less dependence on government programs such as SSI, Medi-Kan or other similar social programs. This also translates to greater incoming revenue for the state of Kansas in terms of a higher taxable income.

I have seen this fact in my work in the field of Deafness in the last 25 or so years. It is not surprising to find that the best and most successful students coming out of the schools for the Deaf today are the ones who were identified very early in their lives, and immediately immersed in an appropriate and accessible communication environment which enhanced their cognitive development. The problem is that these students represent 5% of all the Deaf children today. Clearly, we need to do a better job of early identification and intervention.

This is not speculation. It is fact. I am one of a less-than-a-handful of Managers who are Deaf in a growing global Corporation. I would not have gotten this job if I did not have the skills the Company was looking for. These skills resulted from the implementation of necessary learning strategies as a result of being identified as a Deaf child immediately after birth.

I also have a Masters Degree from the University of Kansas Public Administration program. In fact, I am the only Deaf person who successfully completed this program. This is living proof that early identification and intervention works.

Please pass House Bill 2362. You are investing in Kansas' future by doing so.
Thank you for your consideration of my testimony.

Sincerely,

David S. Rosenthal
425 Boulder
Lawrence, Kansas 66049

HHS
2-22-99
Atch #20

WRITTEN TESTIMONY ON HB 2362 – INFANT HEARING SCREENING

TO: Chairperson Garry G. Boston and Committee Members

FROM: Leonard Hall – Telephone Number # 1-913-782-2600

DATE: February 22, 1999

I support House Bill No. 2362 to provide infant screening for all infants born in Kansas. When the current law on infant hearing screening was adopted in 1990, the central concern of medical centers and the public was the high cost of providing the infant test screening for each infant. As the result of this concern, the legislation passed into law applies only to high-risk infants.

Since the law was adopted in 1990, it has been discovered that more than half of the children who were discovered to have a hearing loss did not fall under the definition of "high-risk infants" and were considered to be normal. Many of these "normal" children with hearing loss were not diagnosed with a hearing loss until they were 3 years or older, causing loss of invaluable time for language development in hearing and speech communication crucial for children's growing years from 6 months to 3 years old. Research shows that language development of hearing and speech communication is most crucial during the first three years of a child's life. The cost of special education needed to make up for the loss of language development during the first three years is expensive.

Fortunately, due to the tremendous technology advances in equipment used for infant hearing screening, the cost of providing infant hearing screening has dropped tremendously to a cost in the $20 to $50 per child range. The hearing test equipment is hand-held hearing and the testing takes a few minutes to determine if the infant has a hearing loss. If an infant is determined to have a hearing loss, the parent can be referred to a specialist for further hearing evaluation.

I know many hard of hearing people who were born with a hearing loss and have difficulty with proper speech and difficulty in hearing with the use of a hearing aid. Early detection of their hearing loss and proper fitting with hearing aids at an earlier age would have been beneficial in improving their language development of hearing and speech communication.

It is time to require infant hearing screening for all infants born in Kansas to give those with a hearing loss an opportunity for better hearing and speech communication.

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Atch#21

WESLEY
Medical Center
550 North Hillside
Wichita, Kansas 67214-4976
Telephone 316/688-2468

February 22, 1999

TO: Health and Human Services Committee
Chairman, Garry G. Boston
Committee Members

Please vote FOR the Universal Infant Hearing Screens.

I am a Developmental Pediatrician, practicing for seven years. I see a variety of children with multiple developmental delays and handicaps. My practice follows a large number of children (over 30 per week).

Identification of hearing impairment early in life is imperative for children. Those children found with hearing impairment early in life can be identified, treated and become effective communicators. The screening process and treatment is necessary for them to be successful in their life endeavors.

I urge you to vote "YES" for the Infant Universal Hearing Screens.

Sincerely,

Valarie Kerschen

Valarie L. Kerschen, M.D.
Developmental Pediatrician
Clinical Assistant Professor of Pediatrics - UKSM/Wichita
Neonatal Follow Up Clinic/Pediatric Developmental Clinic
Wesley Medical Center
550 N. Hillside
Wichita, KS 67214

Phone: 316-651-8579
FAX: 316-651-8543

HHS
2-22-99
Atch #22

To: Chairman Rep. Garry G. Boston and Committee members

From: Lynn Eyrich
At: eyrich@kcnet.com
13656 S. Sycamore
Olathe, KS 66062
(913) 829-8583

Dear Chairman Rep. Garry G. Boston and Committee members:

I heard about this House Bill #2362 which is about to go before the health and Human Service Committee on Monday, February 22, 1999. I would like to express my support for this bill. I feel it is vital that all newborns be screened for hearing loss.

My husband and I are parents of 4 children, 3 of whom are deaf. So much can be gained by early detection of hearing loss. Through early intervention, our family has benefitted from services through the Hartley Family Center at KU. I feel that all families deserve to have the earliest opportunity for these services.

Please vote in support of newborn screenings throughout Kansas.

Sincerely yours,

Lynn Eyrich, Parent

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Atch #23

February 19, 1999

Dear Representative Garry G. Boston and Committee Members:

As a parent of a child who was born deaf from a malicious virus I want to share my testimony that supporting the Newborn Infant Screening Bill (House Bill 2362) is the right thing to do!

At the time of my daughter's birth (1989), I was living in the state of Hawaii. The doctors that were attending my pregnancy and childbirth knewof the virus but failed to explain its ramifications. For many years I have personally struggled with emotions related to that issue. Had the doctors known that this virus would have caused deafness, they could have saved me a tremendous amount of grief and delay. Since the doctors did not identify my daughter's deafness, we lived with the suspicion that something was just not right for sixteen months. It wasn't until we moved to Kansas that she was identified in a screening at our local Douglas County Health Clinic.

If I had those sixteen months to relive again with the knowledge of my daughter's deafness, I believe with all my heart that we could have gotten a jump start on the profound impact a language delay had upon her. I could have also had the opportunity to redirect some valuable energies in preparing myself with the extra time in dealing with the loss, emotions and learning of a new communication system that accompany a hearing loss!

Time is a valuable resource for the human being. It is the one thing we can afford to give our newborns and their families with the identification of a hearing loss through a Newborn Infant Screening law. Let us not overlook that since our time here on earth is so short. Find a place in your hearts for those families and individuals that can benefit from the screening. Know that this is the best and only remedy for us all to combat this injustice. Please support this bill and impact the quality of life for many individuals and their families.

Thank you for the opportunity to share our story and influence your decision.

Sincerely,

Ann Curry
Building #11 Apartment #5
Stouffer Place
Lawrence, Kansas 66044
(785)838-9153
ajcurry@eagle.cc.ukans.edu

HHS
2-22-99
Atch #24

February 19, 1999

Dear Chairman Boston and Committee Members:

It would be so very helping in my opinion, for this bill to pass. My daughter Kim Jo Snelling started to school at the Institute of Logopedic's in Wichita, KS at age 2yrs. That was the first we realized she had a profound hearing loss. She was not excepted in the Public school so at age 7 (approx.) she started to school in KC, KS at St. Joseph school with approximately 30 hearing students. From there she went to Chikasha, Ok. an oral school for the Deaf. Graduated from Southeast High (struggling) where I was told she was not college material! With lots of prayer and emotional stress (her father had died) I was able to get her in at Johnson County Community College, she attended and graduated after four long years of struggle. She learned to sign ASL and increased her vocabulary, she still lives in the Olathe area and has worked in Olathe and Overland Park and is a very dependable, independent person, but is still disappointed in me (her mother) for her lack of Education.

Thank you and Sincerely, Ellie Snelling - Parent

HHS
2-22-99
Atch #25

Feb. 19, 1999

Dear Chairman Rep. Garry G. Boston, and Committee Members;

My son was born severely-profoundly deaf but unfortunately for us, I was a young mother at the time and did not recognize anything until he was a year old. He was very sharp with his eyes and appeared to hear me. I was fooled by his baby babbles, and attentiveness to everything happening around him. He had normal intelligence and it wasn't until we went to a family reunion that I noticed he wasn't responding to noise behind him.

After a trip to see an Ear, Nose, & Throat Specialist in Kansas City, we were told the devistating news that he was deaf. I grew up in a small town and my son was the first deaf person I'd ever seen. This happened eighteen years ago and at that time there were few preschools for deaf children, but luckily I found a program in Sedalia, Mo., and we enrolled him in preschool at one year old.

I feel that he benefited from receiving training at an early age, we were able to communicate in Sign Language unlike other students that are not identified until much later. After my daughter was born five years later, I was surprised that she was signing before a year old, although she was a hearing child, she signed before she spoke.

I'm writing to ask that you support the House Bill No. 2362, to identify infants at birth. From my own personal experiences I know how much this would benefit other parents and children.

Thanks for your support.

Respectfully,

Teresa L. Belt

Teresa L. Belt

HHS
2-22-99
Atch#26

February 22, 1999

Dear Chairman Rep. Garry G. Boston and Committee Members:

I'm writing to you concerning universal hearing screen. My daughter, now 11 months old, was recently diagnosed with moderate to severe hearing loss. Cause unknown. If my wife and I weren't medical professionals we probably still wouldn't have figured it out. Our child's doctors doubted there was a problem, but pursued it and so we were able get a diagnosis by 6-7 months of age. Once she got hearing aids, her hearing behaviors improved dramatically. I hope speech will be possible but we are learning sign language just in case its necessary.

Please allow me to advocate for screening infants.

Richard Lutz MD
9427 Wyncroft Ct.
Wichita, KS 67205-1406

rlutz@kumc.edu

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2-22-99
Atch#27

Kansas Council on Developmental Disabilities

BILL GRAVES, Governor
DAVE HEDERSTEDT, Chairperson
JANE RHYS, Ph. D., Executive Director

Docking State Off. Bldg., Room 141, 915 Harrison
Topeka, KS 66612-1570
Phone (785) 296-2608, FAX (785) 296-2861

"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

HOUSE HEALTH & HUMAN SERVICES COMMITTEE

February 22, 1999

Testimony in Regard to House Bill 2362

Mister Chairman, Members of the Committee, my name is Craig Kaberline and I am presenting this written testimony today on behalf of the Kansas Council on Developmental Disabilities in support of House Bill 2362, enacting the newborn infant hearing screening act.

The Kansas Council is a federally mandated, federally funded council composed of individuals who are appointed by the Governor. At least half of the membership are persons with developmental disabilities or their immediate relatives. We also have representatives of the major agencies who provide services for individuals with developmental disabilities. Our mission is to advocate for individuals with developmental disabilities, to see that they have choices regarding their participation in society.

The Kansas Council on Developmental Disabilities is in total support of House Bill 2362. There is clear evidence that universal newborn hearing screening substantially lowers the age at which children with congenital permanent hearing loss are identified. Children who are identified early and receive intensive early intervention perform significantly higher on school-related tests than children who do not receive such intervention. The current average age for detecting significant hearing loss in children is 14 months. Studies have shown the first two years of a child's life are critical for learning, it is difficult for a newborn to learn when they can not hear what is being taught.

I appreciate the opportunity of appearing before you and would be happy to answer any questions that you may have.

Craig Kaberline
Grants Manager
Kansas Council on Developmental Disabilities
Docking State Office Building, Room 141
Topeka, KS 66612-1570
(785) 296-2608
email: kaberlne@midusa.net

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Atch# 28

February 19, 1999

Dear Chairman Representative Garry G. Boston and Committee Members

As an audiologist who has worked in both clinical and academic facilities, I feel an obligation to write to you to seek your support for the bill on Newborn Hearing Screening in Kansas. The effects of a hearing impairment are devastating if not detected earlier. Unlike visual impairment, where one certainly is aware of a problem early, hearing loss can remain undetected for a months, causing the infant to be unaware of so many precious stimulating experiences. I have seen first-hand the effects of early detection of hearing impairment, the therapy that entails, and the satisfying results for both, parents and professionals. Kansas is known for its progressiveness in health, technology and other areas. Please support this bill that will enable Kansans to feel that their newly born infants have access to early detection of hearing impairment, and the subsequent therapy to help them be productive members of society.

Sincerely,
Glynis Murphy, PhD, CCC-A
Audiologist/Lecturer

PS: While we lived in Newton, I knew that people there trusted your good instincts. Thank you for your years of service. Newton is a very special place for us, and will always be.

HHS
2-22-99
Atch #29

The University of Kansas

February 19, 1999

Dear Chairman Rep. Garry G. Boston and Committee Members:

Reference: HOUSE BILL No. 2362 Newborn Hearing
Screening Act

I am writing to urge your support for passage of the bill to enact universal hearing screening of all newborn infants in Kansas. In my profession of audiology, I see the tremendous burden caused for children and their families by delays in identification of hearing loss. Recent research has led to accurate, cost effective methods of administering brief, noninvasive hearing tests to newborn infants before they are dismissed from birthing centers. Currently, 50% of newborn infants with hearing loss are not identified at birth, and sometimes years of opportune time for development of speech, language, and cognitive growth are lost before the hearing loss is discovered. Research has shown that considerable savings in special educational cost can be avoided by early identification of hearing loss, and early intervention. Your support of the newborn infant hearing screening act will assure that infants with hearing loss are recognized, and their parents will have an opportunity to make important intervention decisions during the infants first 3 to 6 months of life. Thank you for support of this bill for infants and their families.

Respectfully yours,

Larry E. Marston
Associate Professor
Audiology
University of Kansas

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Southeast Kansas
Education
Service Center

947 W. 57 HWY.
Girard, Ks. 66743-2347
316-724-6281 Fax 316-724-6284

February 19, 1999

Dear Chairman Rep. Garry G. Boston and Committee Members:

Research indicates that the identification of hearing loss by six months of age, followed by appropriate intervention, is the most effective strategy for the normal development of language in deaf and hard-of-hearing infants and toddlers. Identification of hearing loss by six months can only be accomplished through universal newborn hearing screening. None of the 13 deaf children I work with met any of the high risk criteria associated with hearing loss. Many of the students were identified well into the critical years for speech and language development, resulting in long lasting language, reading and learning difficulties. Only one infant was fortunate enough to be identified and fit with amplification by 6 months of age. This child was lucky to be born in a local hospital that conducts universal hearing screenings on all newborn infants. Please make it possible for all Kansas children to have access to these screenings. Our future depends upon their ability to learn, communicate and succeed. Please support Universal Hearing Screening Bill 2362.

Sincerely,

Alicia Troike, M.A., CCC-A, CCC-S
Educational Audiologist
Speech Language Pathologist

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2-22-99
Atch# 31

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February 19, 1999

Dear Representative Boston and Committee Members:

The passage of House Bill 2362 is of great importance to the future children of Kansas who will have a hearing loss.

I am a teacher of the deaf/hard of hearing with forty years of experience. In my professional experience and reading of research I have found that there are three main components in the successful education of deaf children. Number one is early identification with parent involvement and consistent educational programming following. House Bill 2362 deals with the first component. A deaf child must have early exposure to language and communication and have the same opportunity to develop these skills as does a hearing child. This infant should not have to be in a "language -less" world during his/her critical language learning period of life.

The effects of a hearing loss on a child's development, especially in the area of language, are great. Language affects every aspect of our lives and it is imperative that the young deaf child be given every opportunity to develop as other children. Infant screening has proven to be cost effective in other states that have initiated it. Life long cost effectiveness for Kansas children will be tremendous! I strongly urge the passage of this bill.

Sincerely,
Grace E. Kneil
6110 Edinburg
Wichita, KS 67220
316-744-1016

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Atch#32

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KANSAS PUBLIC HEALTH ASSOCIATION, INC.

KANSAS PUBLIC HEALTH ASSOCIATION, INC.
AFFILIATED WITH THE AMERICAN PUBLIC HEALTH ASSOCIATION
215 S.E. 8TH AVENUE
TOPEKA, KANSAS 66603-3906
PHONE: 785-233-3103 FAX: 785-233-3439
E-MAIL: kpha@networksplus.net

Testimony on HB 2314
Presented by Sally Finney, Executive Director
February 22, 1999

Representative Boston and members of the House Committee on Health and Human Services, my name is Sally Finney, and I am Executive Director of the Kansas Public Health Association. I am here today to express our strong supports of House Bill 2314, the Childhood Lead Poisoning Prevention Act.

Lead poisoning is one of the most pressing environmental problems facing children in the United States. The U.S. Agency for Toxic Substances and Disease Registry reports that one of every six children in the United States has high levels of lead in their blood. In 1994, the National Conference of State Legislatures released a report, "Lead Poisoning Prevention: A Guide for Legislators." That document cites the following facts about lead poisoning:

- blood lead levels of less than 10 micrograms/deciliter may cause decreased IQ and impair hearing and growth (page 1);
- increasingly higher blood lead levels cause increasingly more severe complications ranging from a reduction in production of hemoglobin, the chemical that carries oxygen to cells, to nervous system damage. It may, in the most serious cases, cause kidney damage and death (page 1); and
- children are more likely to be exposed to lead from exposure to lead-based paint than through any other source (page 2).

The pages noted above are attached for your reference.

Children are at greatest risk from lead exposures because their bodies absorb 3 to 10 times more lead than do adult bodies. Children are also at greater risk because they are more likely to have hand-to-mouth contact. A child who touches a lead-bearing object, like such as a window sill painted with lead-based paint, then sucks his or her fingers is exposed to lead. A child who picks up an object that has been in contact with a lead-bearing surface also will be exposed.

Childhood lead poisoning can impact future generations, because the body can store lead in bone tissue, sometimes for as long as 20 years. It is then released during times of physical stress, such as that caused by pregnancy. This means that a young girl exposed to lead who becomes

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pregnant as an adult can expose her unborn children to lead. Lead poisoning threatens rural, urban, and suburban communities, and it is entirely preventable.

According to the Centers for Disease Control and Prevention, blood lead levels have declined since the 1970's with the implementation of regulatory and voluntary bans enacted on the use of lead in gasoline, household paint, food and drink cans, and plumbing systems. However, threats to our children still exist because unsuspecting homeowners lack the proper education to contain those threats.

Why support HB 2314?

- Provisions of HB 2314 meet federal requirements**, allowing the State to continue existing childhood lead poisoning prevention activities** throughout Kansas and avoiding federal intervention.
- It **does not require** homeowners or landlords to conduct inspections, risk assessments, or abatement.
- Homeowners and landlords choosing to have inspections, risk assessments, and abatement will know that such work is done by **properly-trained individuals**.
- Passage of HB 2314 **enhances the State's ability to successfully compete for federal lead poisoning prevention funds**.
- Its enactment **opens the door for communities to compete for HUD grant funding** for voluntary remediation of older homes of low income families.

The Kansas Public Health Association asks your support of HB 2314.

1. THE NATURE AND EXTENT OF LEAD POISONING

Lead is a highly toxic metal that exists in paints, dust, and soils in and around homes in the United States. If ingested by humans lead disturbs virtually every system in the body and provides no physiological benefit. The most comprehensive study of blood lead levels, the Third National Health and Nutrition Examination Survey (NHANES), estimates 1.7 million children have blood lead levels at least 10 µg/dL or above.[12]

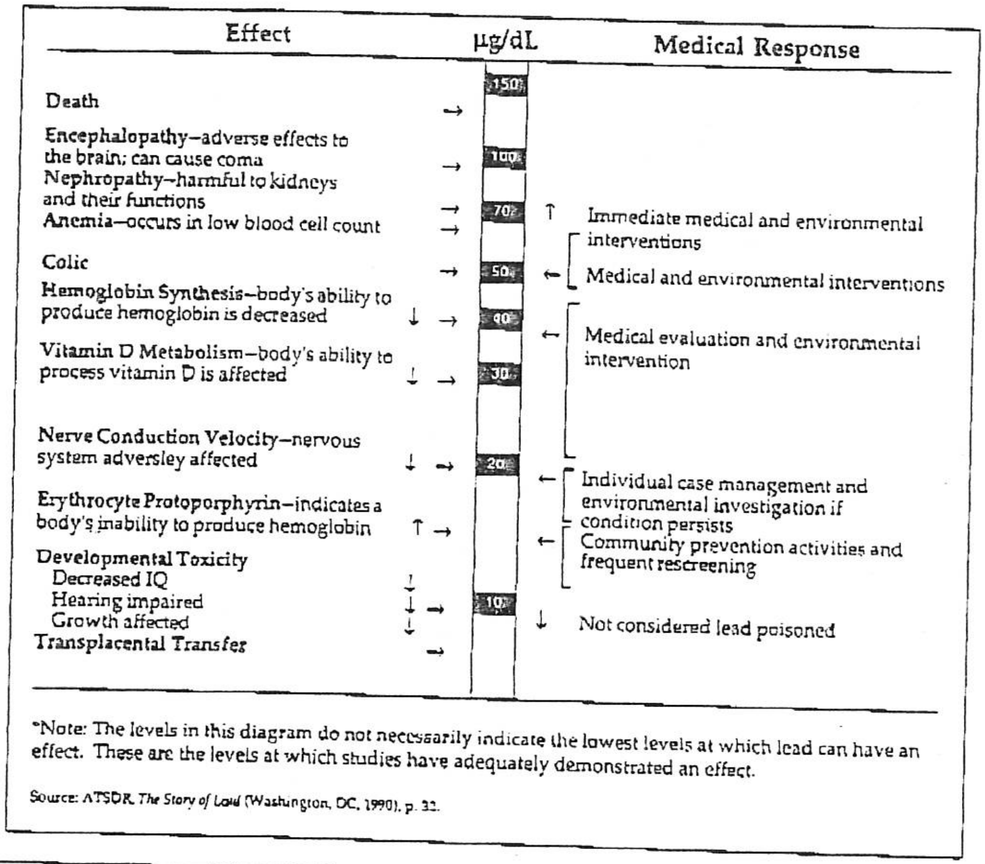
Characteristics of the Metal

Lead has unique properties that increase the severity of the problem. As an element, inorganic lead cannot be processed or destroyed, nor can its chemical structure be changed. Lead also accumulates in the environment. Once released from its natural state it remains indefinitely, continually posing a threat for which there are no natural defenses.[13]

Before the industrial age, exposure to lead was rare. Industrialization, however, released massive amounts of lead into the environment. Lead was used extensively in paints and gasoline, emitted from smelters and factories, used in pipes and plumbing for water systems, as well as other consumer and industrial applications. Large amounts of lead remain in old paint and drinking water

Figure 1

Lead Levels in Blood That Cause Certain Effects in Children*



*Note: The levels in this diagram do not necessarily indicate the lowest levels at which lead can have an effect. These are the levels at which studies have adequately demonstrated an effect.

Source: ATSDR, *The Story of Lead* (Washington, DC, 1990), p. 32.

systems. Dust and soil contain the residues from all these major sources, and natural forces widely disperse dust contaminated by lead. No socioeconomic group, geographic area, or racial or ethnic population is free from lead.

Effects on Children and Pregnant Women

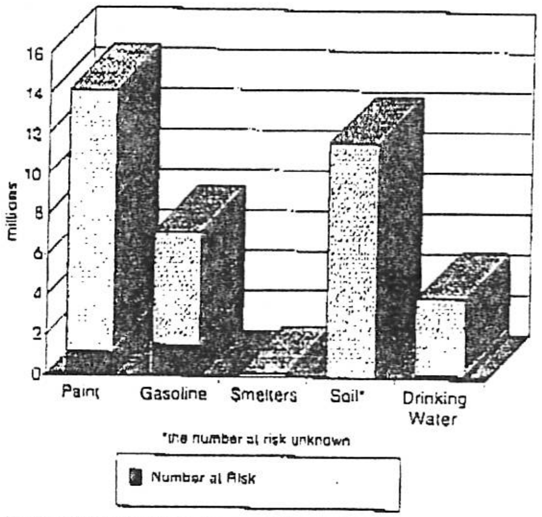
When absorbed into the body, lead usually affects the central nervous system most severely (see figure 1). It is, therefore, particularly harmful even at low-levels to the developing brain and nervous system of young children, infants and fetuses.[14] Children and infants are more likely than adults to be poisoned by lead because they have more hand-to-mouth activities and thereby ingest more lead-contaminated dusts and paints. Their bodies also are more likely to absorb the lead once ingested.[15]

Lead affects pregnant women by causing premature deliveries and lower birthweight and, in extreme cases, causing miscarriages and stillbirth. Research has indicated that low levels of lead in the blood harm a fetus' central nervous system, and the Centers for Disease Control and Prevention (CDC) believes it may have an adverse effect.[16]

Lead poisoning is measured by blood lead content: the number of micrograms of lead in a deciliter of blood (µg/dL). A microgram per deciliter is equivalent to four grains of salt placed in a swimming pool. Extreme levels in children, above 80 µg/dL, can cause comas, convulsions, and death if not treated. Lower levels, between 25 µg/dL and 60 µg/dL, cause adverse effects on the central nervous system, the kidneys, and blood-forming organs. At levels nearing 10 µg/dL, lead decreases intelligence and impairs neurobehavioral development. Other effects linked to low blood lead levels include decreased height, impaired hearing, and an inability to stand upright.[17]

Figure 2

Number of Children Exposed to Lead via Various Media



*the number at risk unknown

Source: Agency for Toxic Substances and Disease Control (1988)

Sources and Reduction of Exposure

The three major sources of lead are lead-based paint, lead particles in dust and soils (mostly contaminated by lead in paints and gasoline), and lead in drinking water. Lead from smelters and other stationary sources, municipal waste and sewage sludge incinerators, and consumer products also contribute to lead into the environment (see figure 2).[19]

Lead-based paint. Lead in household paints is the most frequent cause of lead poisoning.[20] Although the sale and use of lead-based paint was banned in 1978,[21] 4.9 million tons of lead were used in paints, and more than 57 million homes have lead-based paint.[22] Nearly 10 million of these homes are occupied by families with children under seven, and almost four million of these homes have chipping and peeling paint that poses an immediate risk to children.[23] Many children from upper- and middle-income families are being exposed to lead paint and dust from home

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Testimony Presented to:

Kansas House Health and Human Services Committee

Monday, February 22, 1999

By

Richard A. Baker
Co-Chair - Kansas Lead Council

House Bill 2314

I come to you today with three (3) different perspectives regarding the issue of preventing lead poisoning:

1). **Co-Chair of the Kansas Lead Council;**
2). **Former Manager of A Lead Poisoning Prevention Program; and,**
3). **The parent of a lead poisoned child.**

1). Kansas Lead Council

A. **The Kansas Lead Council (KLC) is a large volunteer group of Kansas citizens whose sole purpose and dedication is to see an end to the insidious threat of lead poisoning. While lead poisoning is 100% preventable, the physiological and psychological impact is permanent. The negative social and economic impact to the estimated 10, 600 children in Kansas is devastating and reprehensible! Lead poisoning is empirically known to cause irreversible damage and trauma to our children. The national Secretary of Health and Human Services calls lead poisoning "THE NUMBER 1 HEALTH THREAT FACING OUR CHILDREN TODAY!"**

B. **The KLC is comprised of many different private citizens, organizations, agencies and groups from within the state, representing several thousand Kansas citizens. A few of those represented include: Parents of lead poisoned children; Kansas Public Health Association; Kansas Association for Sanitarians; Kansas Health Institute; KU Medical Center; University of Kansas; Kansas State University; Kansas Association of Realtors; Kansas Banker's Association; Kansas Landlords Association; Kansas Association of Local Health Departments; Prairie Band of Potawatomie; Kansas Homebuilder's Association; Kickapoo Tribe in Kansas; LeadBusters, Inc.; US EPA; Agency for Toxic Substances and Disease Registry; KDHE; Kansas Medical Society; as well as many others.**

C. **The entire membership of KLC is in full support of HB 2314. We strongly encourage the entire Kansas House of Representatives to wholly endorse and support this extremely important legislation which seeks to put an end to the physiologically and psychologically crippling disease which robs our children of their happiness and life!**

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2. **Former Manager of a Childhood Lead Poisoning Prevention Program**

   A. **I have seen the devastation caused by this preventable disease known as "The Silent Killer"! I have witnessed traumatized 2 year old babies who were screaming and fighting while being held down by several nurses as a doctor injects (UP TO 80 TIMES) chemicals deep into the muscles of these babies, in an effort to try to help rid the lead which has stored in the body! I have witnessed that several years after a child has been lead poisoned, children developing kidney disease as a result of the damage caused by lead! I have seen sweet, angelic faces being put into institutions, perhaps for life, because those children were unable to function as a normal human being!**

3. **The Parent of A Lead Poisoned Child**

   A. **I have personally witnessed what no person should ever have to witness; the extreme emotional and physical trauma to the lead poisoned child and the degradation of their families! I can personally attest to the fact that with a lead poisoned child, every day is a on-going raging battle and every battle has to have victims who are losers (losers; a name that lead poisoned children hear all too often!). I have seen my child lose all self esteem and contemplate unthinkable acts, in an effort to be rid of the endless suffering!**

<u>Passage of HB 2314 Will Benefit All of the State of Kansas</u>

1. **HB 2314 will establish a statewide Childhood Lead Poisoning Prevention Program. This Program will provide for the early detection of lead poisoning, <u>BEFORE</u> a child develops lead poisoning and suffers unnecessarily. This Program will help Kansas citizens to identify lead hazards and remove those lead hazards, <u>BEFORE</u> the disease has robbed our children of their intellect and happiness.**

2. **HB 2314 will establish a statewide registry of persons who have been properly trained and who are professionally licensed to identify and remove lead hazards, which will create new jobs and also ensure the competency of those persons. The Program will ensure that the persons performing the lead hazard identification and removal work are aware of cost effective means to prevent lead poisoning, without making the problem worse by performing improper activities.**

3. **The Program will be able to identify the geographical areas of the state of Kansas where the greatest number of children have been lead poisoned (and where our children are at the greatest risk of lead poisoning), and then focus the economic and manpower efforts in those areas, so as to be able to derive the greatest beneficial impact of those valuable resources.**

4. **By having a statewide/state run Program in-place, the best interests of the citizens of the state will be decided by the state, rather than a federal agency whose only real impetus is to follow their congressional mandate.**

5. **By having a this Program, the State of Kansas will also receive the value added benefit of being eligible to acquire literally millions of dollars in newly allocated funds from EPA, HUD, the Federal Centers for Disease Control and Prevention (CDC), as well as public and private foundations, which are specifically earmarked for lead poisoning prevention.**

6. **By having a statewide Program run by a state agency (KDHE), rather than a federal agency (EPA, as it is now), Kansas will also once again be able to receive the federal funding which was removed from the state by EPA last year because the state did not have a program.**

7. **By having a statewide Program run by a state agency, citizens of Kansas will become educated about lead poisoning prevention and then empowered, so that they may protect themselves without the intervention of federal agencies. Through the Program's educational efforts, Kansas citizens will become less dependant on state and federal resources, with the ultimate goal being the end of the life threatening menace of lead poisoning.**

8. **By having a statewide Program, the overall moral, ethical and economic impact on the state will be phenomenal! We will be much better able to fulfill our moral and ethical obligation to allow our children to live and to develop in an environment which is conducive to citizenship and to learning. We will be able to allow our children to live free of the threat of an environmental hazard which robs them of their life.**

FACT: The hazards of lead are known and well documented. Lead effects our children's ability to learn (lessening their chances of receiving higher education!), it reduces our children's IQ potential (lessening their ability to get good jobs, while reducing our state tax receipts!), it eliminates our children's ability to be normally and socially interactive (further segregating those children), it causes emotional and behavioral problems which are proven to be a prelude to incarceration in prisons (creating additional economic burdens!), it eliminates our children's positive contributions to our society (as the federal HHS Secretary said "Who knows how many John F. Kennedys, Albert Einsteins and Martin Luther Kings we could have had, but not for lead poisoning"), and it eliminates our children's God given right to become a normal, productive citizen!

Mr. Chairman and members of the Committee, we implore you:

- **We <u>must</u> do all that can be done to protect our children from permanent damage and irreparable harm;**
- **We <u>must</u> help to ensure the economic viability of our state, by increasing our tax revenues and by making our state eligible to receive the millions of dollars in available funds;**
- **We <u>must</u> ensure that statewide programs are administered by state agency citizens who have the best interest of the state's people in mind; and,**
- **We <u>must</u> allow our children to develop and mature normally, as they are supposed to, something which most of us take for granted.**

<u>HB 2314 must pass this legislative session!</u>

Which of you are willing to wait until your child, your grandchild or the child of a loved one has been subjected to the travesty of lead poisoning and become emotionally and physically scarred for life?

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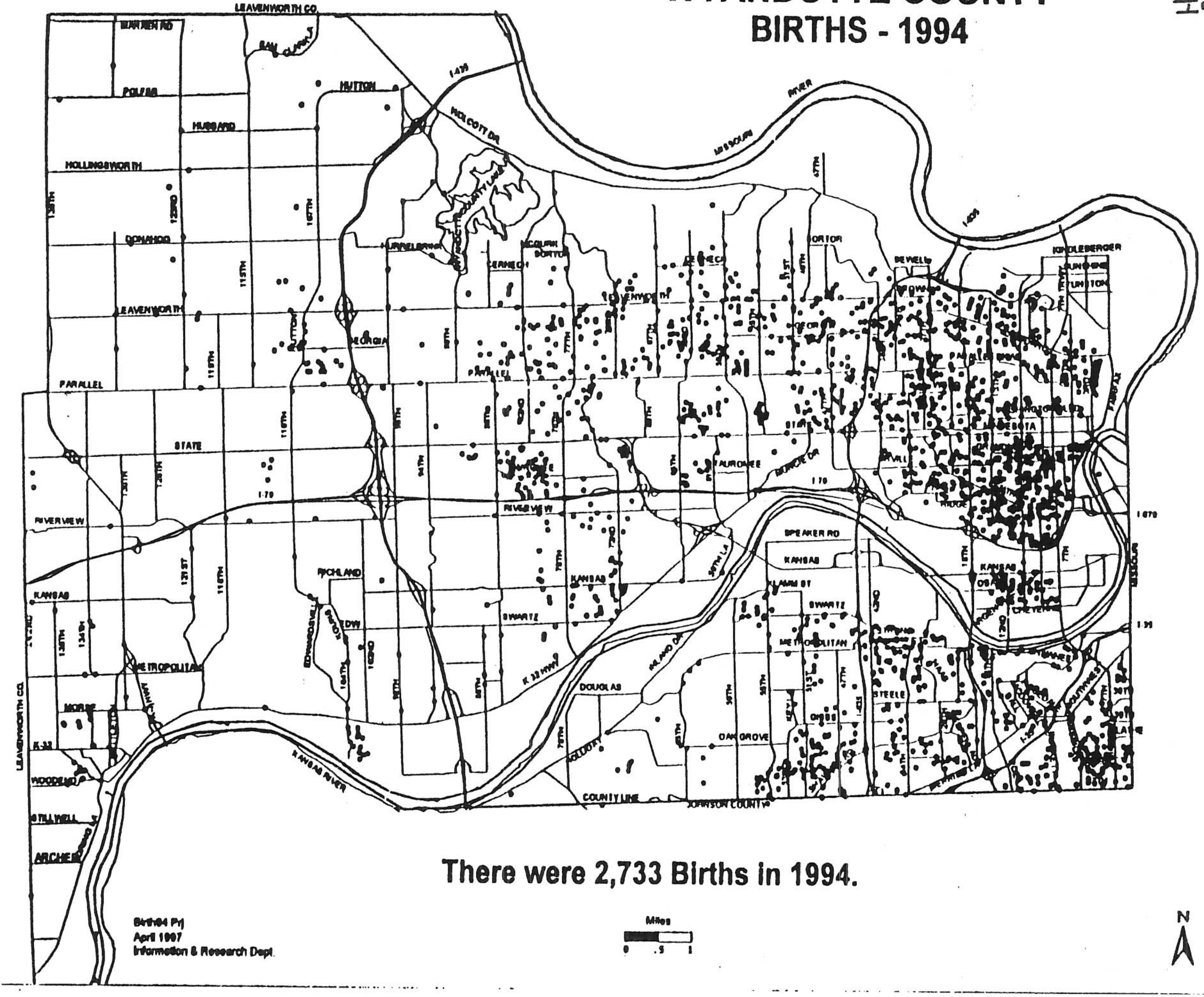
Appendix IV

WYANDOTTE COUNTY
BIRTHS - 1994



There were 2,733 Births in 1994.

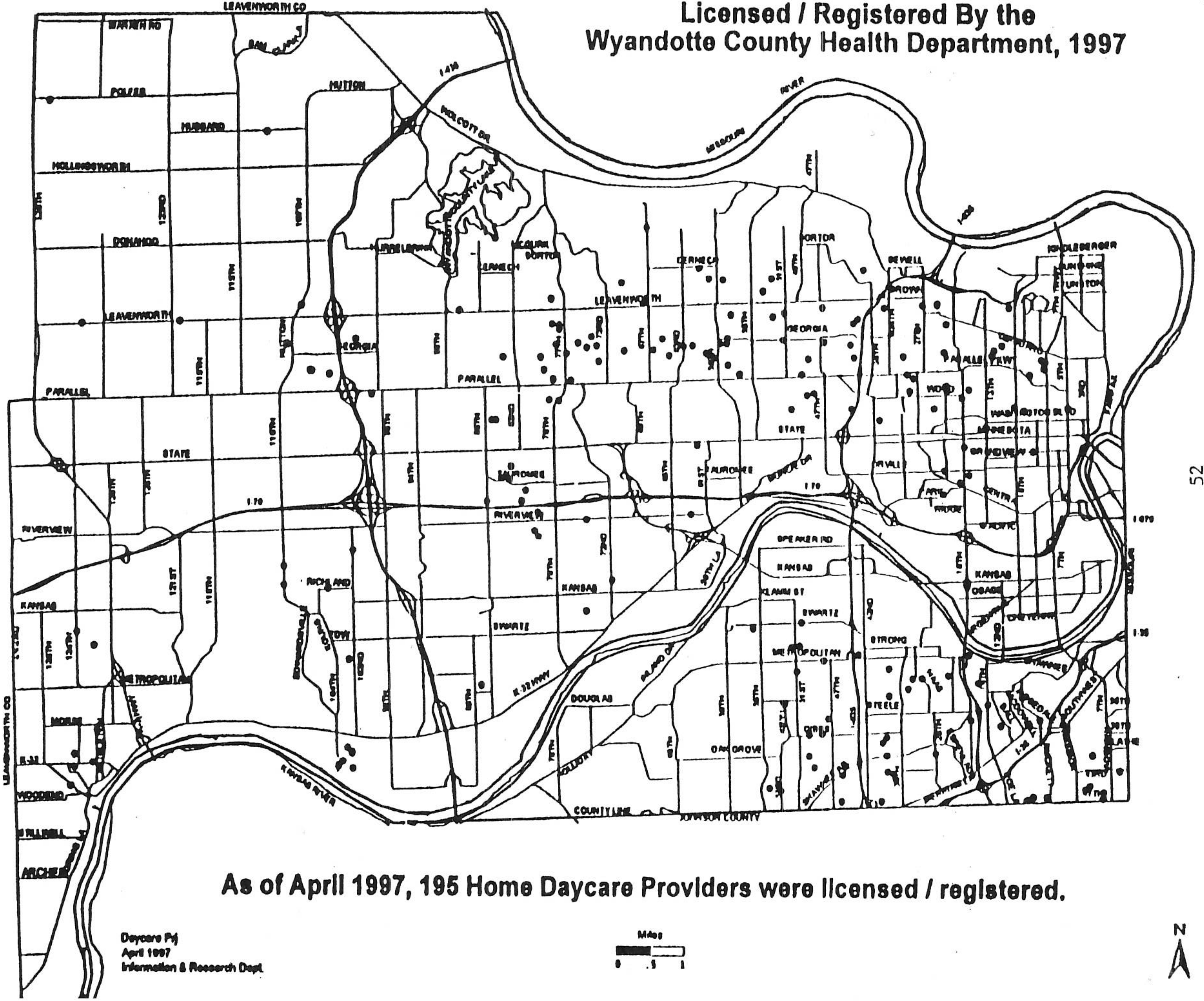
Birth94 Prj
April 1997
Information & Research Dept.

Appendix V

35-2

Wyandotte County, Home Daycare Providers,

Licensed / Registered By the Wyandotte County Health Department, 1997



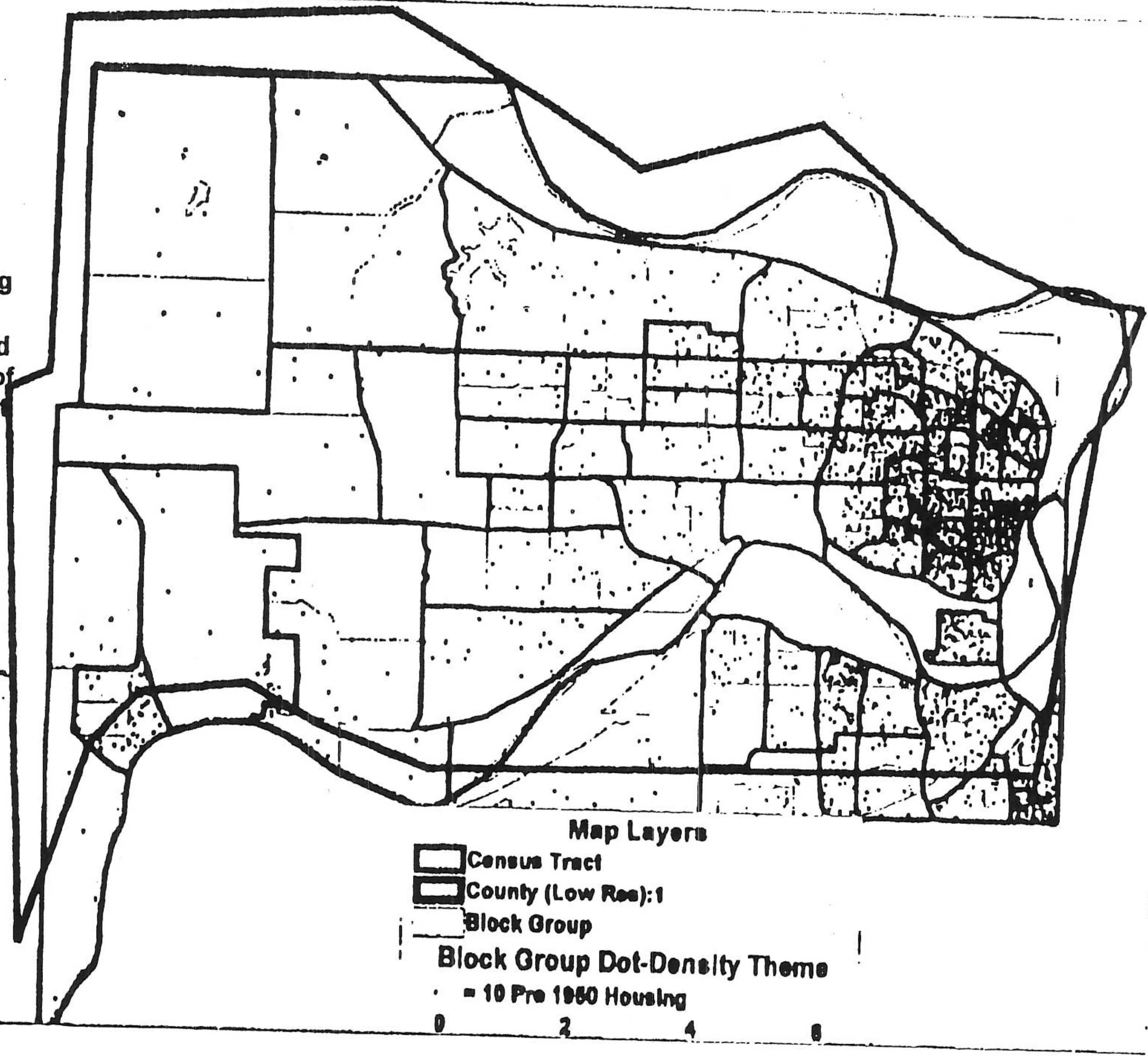
As of April 1997, 195 Home Daycare Providers were licensed / registered.

35-3

Appendix III

Kansas City, Kansas
Wyandotte County
23,463 Pre 1950 housing

Source: Information and Research Department of the Unified Government of Wyandotte County/ Kansas City, Kansas



February 19, 1999

Statement of support for House Bill No. 2314

By Penny Selbee RN
Native Topekan
5626 SW Hawick Ln.
Topeka, Kansas 66614

Member - Kansas Public Health Association

I would like to testify on behalf of House Bill No 2314 for the children in this community and other communities across the State of Kansas. I do not want to spend your valuable time providing you with information that you already have but I will summarize some vital points.

- Lead poisoning is the one of the most common and preventable pediatric health problems today
- Small amounts of lead, once thought to be harmless, can cause serious damage to our children without any evident symptoms. There are usually no symptoms unless a child is severely poisoned.
- Lead poisoning is widespread. No socioeconomic group, geographic area, or ethnic population is spared.
- Children ages 6 months to six years are the most vulnerable.
- Education is crucial to lead poisoning prevention.

The development of community programs to educate parents, child care providers medical providers and all those involved in home renovations is important to our success in protecting our children from needless developmental delays, learning problems, hyperactivity and discipline problems.

As I look at my new grandson I feel blessed that I am able to inform my daughter about how to protect her newborn. She will know not to use hot water for food preparation. In older homes with leaded water pipes, hot water can carry lead into the juice, formula or other foods. She will know that contaminated dust and soil cause 85% of all cases of lead poisoning in children - no playing in the bare dirt outside that older home where past years of lead paint chips now lurk in the soil. She will be aware that the dust in between the storm window and the casement window of an older home is likely to be highly contaminated with lead dust from the friction of up and down. She will know that hand washing before eating is an

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important prevention of ingestion of lead contaminated dust. I hope that she will remember that remodeling projects in that older home can have devastating effects on her son if not managed properly.

Your passage of HB 2314 will allow the State of Kansas to develop programs of education and training which will protect the children of the State. I know that the construction worker who is remodeling that kitchen would never intentionally poison a child and I know that the mother who plays in the dirt with her two year old - building roads for those match box cars would not even think of poisoning as a consequence.

Education and the rules and regulations proposed in the bill will go a long way to protect Kansas' most valuable asset - her children. With the provisions of the bill in place, Kansas will qualify for additional prevention moneys from the Federal government. Please pass this bill. Our entire population deserves a concerted, organized effort for prevention of lead poisoning.

Testimony presented to

House Health and Human Services Committee

Febuary 22, 1999

by

Barry Brooks
Kansas Childhood Lead Poisoning Prevention Program
Kansas Department of Health and Environment

House Bill 2314

House Bill 2314 addresses childhood lead poisoning prevention in Kansas. This issue was brought before you several years ago. The provisions of HB 2314 bring this issue to you again, but in a different context. HB 2314, if passed, provides the opportunity for the KDHE to address childhood lead poisoning as a public health issue, rather than an environmental abatement issue. The components of this bill address both the health of children and the environments they live in.

The Centers for Disease Control and Prevention (CDC), estimates 4.4% of children in the target group have elevated levels of blood lead. CDC estimates applied to Kansas would indicate 10,600 children in the age group have elevated blood lead levels. The target group includes children ages six months to six years. Children ages 1-3 are usually at the highest risk. These children are exposed to lead through a number of routes, but dust in the home contaminated by deteriorating lead based paint is the major source of exposure The provisions of this bill are directed at protecting those children through screening, parent education and management of environmental lead exposure.

The consequences of lead poisoning in children include adverse effects on learning, behavior and growth. High levels of lead poisoning can cause seizures, coma and death. The benefits of preventing lead poisoning include avoided medical and special education costs, increased lifetime earnings and reduced infant mortality.

HB 2314 also addresses issues related to training, worker certification, and work practice standards. This portion of this bill is directed at meeting the requirements of Section 402 of the Toxic Substances Control Act as required by the Residential Lead-based Paint Hazard Reduction Act of 1992, administrated by EPA. This federal law requires certification programs for contractors to be in place by August 31, 1998. EPA will establish the program in Kansas if we do not. Federal grant funds are available for the states to establish such programs.

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Kansas has approximately 800,000 dwellings painted with lead based paint. It is important that children are not unnecessarily exposed to lead contaminated paint dust generated by unsound business practices. Currently, Kansas residents must rely on certification programs in Missouri Iowa, Nebraska, and Oklahoma to provide recommendations for companies that have demonstrated their ability to work safety with lead contaminated environments. Homeowners, contractors, and painters conducting remodeling or renovations will not be required to obtain certification for those services. HB 2314 will provide education for individuals conducting home renovation, remodeling.

In June 1997, the Kansas Lead Council was established by Secretary Mitchell. The Lead Council was formed to promote communications between KDHE, industry, EPA, local health departments and grass roots organizations representing the public. The Council serves as a sounding board for the voluntary members. The Council has met eight times to discuss lead poisoning prevention in Kansas.

The role of local health departments in childhood lead poisoning can not be overstated. Local health department staff provide parent education, blood screening, medical management and environmental assessments. Our past support for local health departments has been through sample testing in our laboratory, providing lead inspector training, assisting with public education and providing consultation regarding medical and environmental management. We have not had funds available to support local activities for medical and environmental follow-up. Passage of HB 2314, establishing a statewide childhood lead poisoning prevention program, will open doors for potential funding for services at the local level from HUD and CDC. Local health department personnel will be exempt from licensing fees.

In summary, passage of HB 2314 will provide a comprehensive program directed at reducing childhood lead poisoning. Childhood lead poisoning will some day be a thing of the past. Until then, many children will benefit from a coordinated effort to reduce exposure to environmental lead. HB 2314 contains the tools to support that coordinated effort. This bill carries a "Sunset" provision of 2004.

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**Christian Science Committee on Publication
for Kansas**

820 SE Quincy St., Suite K
Topeka, Kansas 66612-1158

e-mail cscom@cjnetworks.com

Phone 785-233-7483
FAX 785-233-4182

To: House Committee on Health and Human Services

Re: House Bill 2314

It is requested that subsection 3(a)(4) of this bill, page 2, lines 23-25, be amended to read as follows:

> "(4) 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 grounds that such screening or testing is contrary to the parent's or guardian's religious beliefs and practices;"*

The requested amendment is the same wording as approved by the Senate in SB 437 of the 1998 session. That bill was stricken from the House calendar near the end of the session.

We believe it important to state at the outset that those with religious objections will not be required to participate in screening and testing that may be included in the program established under the authority provided by this bill.

Your favorable consideration of this request will be greatly appreciated.

Keith R Landis

Keith R. Landis
Committee on Publication
for Kansas

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2-22-99
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Salina - Saline County Health Department
We are good for your health!

Salina - Saline County Health Department
125 West Elm
Salina, Kansas 67401

Administration
913-826-6600
Animal Shelter
913-826-6535
Clinic Services
913-826-6602
Environmental Health
913-826-6604
Home Health Agency
913-826-6606
FAX
913-826-6605

Testimony presented to:

House Health & Human Services Committee

February 22, 1999

by

Jolene Funk
Registered Sanitarian, Environmental Supervisor
Salina - Saline County Health Department

House Bill 2314

I am here, speaking in support of **House Bill 2314**, and doing so in 3 separate capacities — representing Kansas Association of Sanitarians, as co-chairman of the Kansas Lead Council, and as a local sanitarian from the Salina-Saline County Health Department.

Representing the Kansas Association of Sanitarians as a member and on the Executive Board, I would like to express support of this bill because of the impact and assistance it can have for Sanitarians across the state. Approximately 80% of all Risk Assessors trained in the State of Kansas are Sanitarians. Most of these operate on the local level, often in isolation and with no chance for additional training or education. Having a program at the state level will allow better access for Sanitarians to new information and necessary re-training. It can also provide the general coordination, support, and tracking necessary for a problem as wide-spread as lead contamination from lead-based paint.

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Salina - Saline County Health Department
125 West Elm
Salina, Kansas 67401

Administration
913-826-6600
Animal Shelter
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Clinic Services
913-826-6602
Environmental Health
913-826-6604
Home Health Agency
913-826-6606
FAX
913-826-6605

As co-chairman of the Kansas Lead Council, I would again urge passage of **House Bill 2314.** Through discussion, debate and review, the Council offered input to the Secretary. One recommendation included the omission of local health departments from fees for certifying health department employees who were Risk Assessors. Most health departments would not have adequate funding to maintain certification and would have to drop that portion of the program for lack of funds. Input from the Council came from a variety of individuals, contractors, realtors, and related business operators.

Finally, **as a Sanitarian in a local health department**, I support this bill. I have worked with families of children with elevated blood levels (EBL's) for the past 5 years and I know the frustration of needing help with problems associated with the home lead investigations and having no one to turn to. While averaging 5 - 8 investigations a year, unusual situations are always occuring. In the past year we have had a contact resource at KDHE which has been extremely helpful. However, without this bill, we lose the funding (and ultimately the program) at the state level for the lead program that was just started. All control will leave the state and end up in EPA's hands. Fees for certification WILL have to be paid, and any problems at the local level will have to be called into the EPA's regional office — does anyone believe we will do that? Most of the questions or problems will just go unanswered. With state control of the program and coordination at that level, more children will be served and with better results. At the Salina-Saline County Health Department, we were contacted by 4 surrounding counties for assistance with lead investigations before the current state support was available. We were not able to help because of time and travel limitations and workload. If the current level of staff and assistance can be retained through the passage of this bill, local health departments would benefit from it.

Thank you for your time and attention.

LEADBUSTERS
Lead-Safe Homes... Healthier Children

February 22, 1999

Dear Chairman Boston and HHS Committee Members,

On behalf of LeadBusters, a not-for-profit organization dedicated to the prevention of childhood lead poisoning, I urge you to **support House Bill No. 2314**. Childhood Lead Poisoning Prevention Legislation is desperately needed in the state of Kansas. Here are the facts:

Fact: **Over 10,000 children under the age of six in the state of Kansas are projected to have dangerous levels of lead in their bodies, causing neurological impairment.** In turn, this can cause developmental and growth disturbances, learning disabilities and behavioral problems. These are long-term problems with long-term costs to the state and to taxpayers of providing health care, special education and other types of support. Since lead poisoning is totally preventable, **the cost of providing prevention education is minute in comparison to the costs of dealing with a lead poisoned child during his or her lifetime.**

Fact: The most recent GAO Report indicates that as many as **85% of high-risk children are not being screened by their Medicaid providers**, even though they are required by contract to do so. Without a lead program in Kansas, providers will not receive the education and support they need to properly screen children.

Fact: **The state of Kansas is not eligible for millions of dollars in federal assistance to address lead poisoning prevention issues because legislation is not in place**. Without state or federal funds, Kansas does not have the resources to provide and/or encourage the screening of children. Furthermore, even when children are identified as having elevated levels of lead in their blood, or are in a hazardous environment, Kansas does not have the resources to provide environmental assessments that identify hazards and produce recommendations for eliminating the hazards.

Fact: **By not having legislation in place, the state of Kansas has been forced to comply with federal law and program requirements in regard to licensing lead abatement professionals.** Because the fees assessed by the federal government are extremely high, most professionals are choosing to not work in the state of Kansas.

LeadBusters has been involved with parents, neighborhood leaders, public and private health care providers, environmental specialists and others since 1994. The common issue among Kansas residents is the frustration over a lack of legislation and programming. **Please support House Bill 2314 so we can protect the health and well-being of our children!**

Cindy Singer

Cindy Singer
Executive Director

HHS
2-22-99
Atch #40

KSNA
KANSAS STATE NURSES ASSOCIATION

700 SW Jackson, Suite 601
Topeka, Kansas 66603-3758

785/233-8638 * FAX 785/233-5222
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the Voice of Nursing in Kansas

Debbie Folkerts, A.R.N.P.--C.
President

Terri Roberts, J.D., R.N.
Executive Director

FOR MORE INFORMATION CONTACT:
TERRI ROBERTS, J.D., R.N.
Executive Director
700 SW Jackson, Suite 601
Topeka, KS. 66603-3758
February 22, 1999

HB 2314 CHILDHOOD LEAD POISONING

Written Testimony

Chairman Boston and members of the House Committee on Health and Human Services:

Childhood lead poisoning resulting from environmental exposure is estimated by the Centers for Disease Control (CDC) to affect 4.4% of children ages six months to six years. Preliminary data shows that as many as 15% or 35,000 Kansas children may have blood lead levels above the action level of 10 mcg/dl.

Lead poisoning is one of the most common and preventable pediatric health problems today. Lead is a highly toxic metal, producing a range of adverse health effects, particularly in children and fetuses. Effects include nervous and reproductive systems disorders, delays in neurologic and physical development, cognitive and behavioral changes and hypertension. Most lead poisoned children do not appear to be sick. There are usually no symptoms unless a child is severely poisoned.

The risk to Kansas children is great. Risk factors include: living near lead-based industrial facilities or having a family member employed in such facility, living in older houses where lead solder was used in the plumbing and exposure to lead-based paint. Lead-based paints were widely used and applied to homes constructed prior to 1978. The greatest risk factor is the deterioration of lead based paint as it chips, flakes and becomes aerosolized.

KSNA supports passage of HB 2314. It will allow Kansas to continue to receive federal dollars to support existing efforts in education of the public and of health professional, for continued blood lead screening, and in data collection across the state. This bill allows Kansas to retain control over its lead abatement efforts, versus the federal government from mandating and taking control. Passage of HB 2314 will also the state to seek additional funds to help address the problem of environmental exposure to lead in the home through enhanced training of home owners and building professionals, in addition to the concerted effort that is required by to conduct blood screening activities.
We encourage you to favorably pass HB 2314.

THANK YOU.

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2-22-99
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NATIONAL CONFERENCE OF STATE LEGISLATURES

1560 BROADWAY SUITE 700 DENVER, COLORADO 80202
303-830-2200 FAX: 303-863-8003 WWW.NCSL.ORG

Memorandum

DATE: February 19, 1999

TO: Health and Human Services Committee, Kansas House of Representatives
The Honorable Gary Boston, Chair

FROM: Doug Farquhar, NCSL

RE: State Adoption of TSCA Title 402/404 Lead Hazard Reduction Programs

The following is general testimony on TSCA Title IV Lead Hazard Reduction and state lead hazard reduction programs. This is offered in response to the committee hearing testimony on HB 2314, The Childhood Lead Poisoning Prevention Act.

Congress enacted the Residential Lead-Based Paint Hazard Reduction Act of 1992 as Title X of the Housing and Community Development omnibus bill. It directs the Department of Housing and Urban Development (HUD), the Department of Labor through OSHA, and the Environmental Protection Agency (EPA), among other agencies, to implement a lead hazard reduction program. Title X amends TSCA to add a new section, Title IV, which directs the EPA's activities on lead.

Under section 404, Congress gave the states (and federally-recognized Indian Tribes) the <u>option</u> of administering and enforcing sections 402 and 406. Section 406 addresses a lead hazards information pamphlet. Section 402 provides for the accreditation of training providers, the training of lead inspection, risk assessment and abatement professionals, and the certification of these professions. It also provides for enforcement of these provisions.

EPA has been providing funds to states (including Kansas) to establish the infrastructure to operate these programs, meaning the money could be used for setting up screening programs, medical case management programs, activities to develop legislation, etc. EPA will begin administering and enforcing programs in states as of August 28, 1999.

As of today, 37 states and the District of Columbia have enacted legislation to adopt a section 402-type program. Ten states have introduced legislation for the 1999 session. Kansas, New Mexico, Nebraska, New York will be seeking legislation to implement a

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402/404 type program. Six states, Alaska, Montana, Idaho, Nevada, North Dakota and South Dakota, are currently not seeking legislation and will presumably have an EPA-administered lead hazard reduction program.

Lead poisoning remains the most serious environmental threat facing America today. It is also entirely preventable. Estimates of up to 890,000 children are afflicted with low-levels from lead-based paint, gasoline, drinking water and exhaust from smelters. Low-levels have been shown to cause deficiencies in intelligence, lessen reading and learning abilities, impair hearing, and leads to hyperactivity and behavioral problems.

The Importance of Legislation

Legislation specifies and responds to the particular needs and concerns facing the state regarding childhood lead poisoning. It reflects the economic and political ideologies represented through the legislative process that cannot be accounted for at the federal level. For a program like lead poisoning prevention, which has a federal mandate forcing a response, local interests can only be effectively represented through state legislation.

Congress passed the Residential Lead-Based Paint Hazard Reduction Act, or Title X, with the intention of states administering its components. However, it allowed states to opt out if they decide not to enact a legislative program.

Title X does not react to lead-poisoned children as much as prevent children from becoming poisoned. The problem is not, according to Title X, whether there are lead poisoned children, but if there is older housing stock or other lead hazards that have the potential of poisoning young children. In the United States, a majority (80%) of housing was built before 1978, and 42% before 1960. (92% of lead used in housing was used before 1960.)

But are children being poisoned? The Third National Health and Nutrition Examination (NHANES) study, which screened over 13,000 children, estimated that 8.9% of children between 1 and 5 years of age have blood lead levels greater than 10 µg/dL, the level of concern identified by the Centers for Disease Control and Prevention (CDC). These numbers represent a continuum; children currently poisoned will be replaced by new cases of poisoning.

If lead poisoning is a concern in United States, should state legislatures address the issue?

As noted above, lead poisoning is a continuum; the poisoning persists unless remediated. Legislation is necessary to provide state agencies the authority to address and remediate poisoning over the long time required to neutralize this problem. Legislation provides the funding vital to keep a program alive, whether it be from fees or from the general appropriation.

And, as mentioned before, legislation would also allow the individual states to develop rules that reflect local concerns, both economic and political. It can incorporate the interest and specific needs of its population. It can provide effective responses to specific concerns raised by training programs, the remediation work force, and the citizens of the state.

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Finally, Title X requires for EPA to operate and administer a training, certification and accreditation program in any state without such a program. Legislation will allow for a state-administered program, rather than a generic program run by EPA providing a facade of safety.

Federal Legislation that may affect a state's legislative decisions

The key to all federal initiatives regarding lead poisoning has always been the states. Congress has acknowledged, since the passage of the *Lead-Based Paint Poisoning Prevention Act* in 1971, that states more effectively regulate local screening and medical case management than the federal government does.

In 1992, Congress and President Bush took an aggressive stance on lead poisoning by enacting the "Residential Lead-Based Paint Hazard Reduction Act of 1992," better known as Title X. The President, after signing Title X, said it would "reduce the risk of lead-based paint poisoning," "would focus inspection and hazard reduction efforts by HUD on older housing stock where the incidence of lead is the greatest," and, most importantly to us, would "support the development of state programs to certify contractors who engage in lead-based paint activities."

In reality, the bill redirects state, local and federal lead poisoning prevention efforts to focus on lead in housing and soils, which causes a majority of low-level poisoning. Moreover, it changes the philosophy from total abatement (as HUD previously recommended) to a program of abatement and in-place management. It calls for research on the dangers that renovation and remodeling create when they disturb lead-based paint. It requires disclosure of lead whenever a house is leased or sold.

Most importantly, it directs the U.S. Environmental Protection Agency (EPA) to establish health-based standards for lead reduction activities that everyone--federal agencies, state programs, local organizations--can rely on and accept.

Specifically, EPA must:

- promulgate regulations to identify paint, dust, and soil hazards and dangerous levels of lead (the health-based standards);

State Programs

- EPA will promulgate a model state program that any state may adopt to administer and enforce a program under Title X;
- the model program will utilize existing state accreditation and certification programs where possible and encourage reciprocity among states;
- states that seek to administer and enforce standards and regulations under this law may submit an application to EPA for authorization of their program; EPA will have 180 days to approve or disapprove the program, based on whether the state plan is as protective of human health and the environment as EPA's model and provides adequate enforcement;
- EPA will monitor state programs and withdraw authorization when necessary;
- EPA is authorized to make grants to states to carry out authorized programs; and

- if a state does not have an authorized program, EPA will establish a federal program for that state.

Training, Certification and Abatement Standards

- promulgate regulations to ensure that individuals engaged in lead-based paint abatement activities are properly trained, that training programs are accredited, and that contractors are certified;
- promulgate regulations for accreditation of training programs that will include workers, supervisors, and inspectors and planners; and
- impose fees on training programs; or have states impose fees if they have an authorized training program.

Renovation and Remodeling Activities

- promulgate guidelines for conducting such activities;
- conduct a study on the hazards of these activities; and
- revise the earlier guidelines.

Disclosure Regulations

- promulgate regulations on disclosure requirements in all housing built before 1978 upon its sale or lease; and
- provide any purchaser or lessee an information pamphlet, disclose the presence of known lead-based hazards, and allow the purchaser 10-days to have a risk-assessment done.

Laboratory Accreditation

- establish a lab accreditation process within 2 years and conduct evaluation within 3 years;
- the National Lead Laboratory Accreditation Process (NLLAP) will be a two-step process:
  - lab must participate in the Environmental Lead Proficiency Analytical Testing Program (ELPAT) sponsored by AIHA
  - pass an on-site audit by an organization recognized by EPA
- EPA will produce a list of labs recognized under the NLLAP program.

EPA Approval

Any state that seeks to administer and enforce the standards, regulations, or other requirements for training and certification of contractors and inspectors may apply for approval from the administrator of EPA. The administrator grants approval if the state program is *at least as protective of human health and the environment* as the federal programs and provides adequate enforcement.

That is all EPA has to go on. It leaves them (and the states) great flexibility and much uncertainty as to what will be and won't be considered "acceptable" to EPA. However, Title X seems fairly clear on certain issues.

Certification of Individuals

Title X requires EPA to ensure that individuals working in lead-reduction activities are:

- properly trained,
- that training programs are accredited, and
- that contractors are certified.

Imposing Fees on Certified Contractors

EPA or states may charge fees for any discipline (inspector, worker, contractor) within the definition of "certified contractor." Fees cannot be charged against any state, local government, or nonprofit training program, only ones for profit. California got around this issue by charging fees on the students, collected by the training provider.

The state may waive the fee against contractors who train their own employees.

Enforcement Fees Determined by States

Below is a list of enforcement penalties defined by state law.

GA	$10,000 a day
IL	Class A misdemeanor
IA	$5000 a day per violation; no criminal
LA	$1000 to $5000 a day per violation
MN	violation as a public health nuisance
NE	$500 to $5000 1st violation $5000 to $10,000 2nd violation
OH	$1000 or 6 months imprisonment for 1st violation $1000 to $ 5000 or 6 mos. to 3 years for 2nd violation
PA	$1000 to $5000 for 1st violation $5000 to $10,000 for 2nd violation
OR	$ 5000 per violation
TX	$2000 for 1st violation $10,000 for 2nd violation
WI	$500 for 1st violation $5000 for 2nd violation

Grants provided by HUD under Title X

HUD has been authorized to provide grants to states and local governments to evaluate and reduce lead-based paint hazards in housing. For FY 1993, $90 million was appropriated to HUD for grants; $93 million was appropriated in 1994; FY 95 $139 million; FY 96 $51 million; FY 97 $51 million; FY 98 $50 million. For this year, FY 99, HUD announced $56.3 million in grants being available. Applicants receiving funding must have an authorized state program regarding training and certification.

HUD selects applicants through a variety of qualifications, and Title X identifies several:

- the extent of lead-based paint in housing and severity of the problem;
- the extent to which the activities will reduce risk; and
- the ability to leverage state, local, or private funds to support activities.

Local governments can apply if their state does not have a program, however, they must use persons certified by an approved program. Individuals are not eligible for grants.

Uses of HUD Grant Money

Title X lists the activities the grant money may be used for:

- to perform risk assessments and inspections;
- to provide interim control of lead-based paint hazards;
- provide for abatements, or to reduce hazards in units undergoing renovations;
- ensure that risk assessments, inspections and abatements are carried out by certified contractors;
- monitor blood lead levels of workers;
- assist in the temporary relocation of families;
- educate the public on the nature and causes of lead poisoning and measures to reduce exposure to lead; and
- test soil, interior surface dust, and the blood lead levels of children under 6 years of age residing in target housing after lead reduction activity has been conducted.

Federal Properties

Federal properties–Department of Defense, HUD, and Indian housing–must be inspected and abated upon sale to the general public or if they are to be rehabilitated with federal funds. The Department of Defense has made a commitment to inspect and abate their properties, yet did not receive any appropriations to do so under either Title X or their regular budget. DOD will issue technical guidance letters to assist its personnel with lead-based hazards.

Problems Other States Have Encountered While Developing Legislation

As of today, 37 states and the District of Columbia have adopted comprehensive legislation that will likely be approved from EPA. Eight of these states passed legislation prior to Title X, 29 passed legislation since Title X, and almost every state has introduced, but not passed, lead hazard reduction legislation.

Each has had to address their own unique situations in developing legislation. Each has identified constituencies that would be affected and addressed their concerns.

Massachusetts passed its law in 1971 but didn't require training and certification until 1988, after it found children being more poisoned from abatements than from intact lead-based paint. Its requirements are so stringent that some homeowners abandon

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their homes and landlords often refuse to rent to persons with young children or who may have young children. The legislature responded by lessening these requirements to encourage people to remain in these units and rehabilitate them rather than abandon them.

Maryland also has a comprehensive lead program. Much of their program responds to lead-related litigation in the city of Baltimore. Property owners in the state may participate in a program that requires their units to meet state standards of lead-safe; in turn, their liability for lead-based paint related claims is limited to $17,500.

New Hampshire does allow person owning four units or less to abate; however, they must be trained and follow the rules for abatement.

The Louisiana statute is the only one which specifically addresses disposal. Persons doing abatements, upon application for a permit, must demonstrate their ability to properly dispose of the lead-abatement waste.

California also decided to assess fees against manufacturers engaged in the "stream of commerce of lead or products containing lead . . . which have significantly contributed . . . to environmental lead contamination." The fee essentially became assessed against the petroleum and paint industry, which accounts for 99% of lead consumed historically. The paint manufacturers sued, claiming that it is unconstitutional, but the Court of Appeals found for the state. Fees are being collected from the paint and petroleum industry at approximately $16 million annually.

Minnesota feared that state-sanctioned training and certification industry may be too burdensome to regulate, and has come up with a unique idea: swab teams. This bill provides housecleaning materials to low-income residents, and educates them on the hazards of lead. It is a very low-cost program; most of the cleaning materials are being donated. And it is lowering blood lead levels.

Several states have enacted legislation, but it is lacking according to EPA. Utah, Nebraska and Arkansas' bills simply amended their asbestos statute, making a wholly irrelevant law. North Carolina law simply said, "to adopt TSCA Title IV." The legislature defeated the bill and drafted a more appropriate law. Oklahoma's bill exempted residential housing.

Most states have adopted laws that go beyond the EPA requirements to include screening, surveillance, medical case management, environmental case management, and remediation requirements; essentially a comprehensive lead hazard reduction program. Funding mostly comes from the federal government and fees, but some states, California most notably, enact other sources of funding.

No state has adopted a law that mirrors EPA. Each has addressed their state's own regulatory, administrative and health concerns. States with much lead-based paint in older homes focus their programs there. States with a large rural population provide much outreach to local communities. Larger states use the county health departments to administer the program.

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From: "Jane Campbell" <campbell@hit.net>
To: "Judy Showalter" <showalter@house.state.ks.us>
Date: Thu, Feb 18, 1999 1:20 PM
Subject: House Bill #2362 (Newborn Infant Hearing Screening Act)

February 18, 1999

Dear Representative Showalter:

I am writing to strongly encourage support of House Bill #2362, the Newborn Infant Hearing Screening Act. Permanent congenital hearing loss the is most frequently occurring birth defect in the United States today, affecting nearly 12,000 babies annually. Although the technology exists to identify this disability shortly after birth, the average age at identification is two and one-half to three years, and many children are not identified until nearly the age of six years. Many studies have shown that, if normal language development is to occur, intervention must begin before age six months. When hearing loss is diagnosed after the age of six months, it is difficult, and often impossible, for children to acquire the language, social, and cognitive skills which form the basis for later success in school and in society. Hearing impaired infants may be fitted with appropriate hearing aids as young as four weeks of age. With appropriate early intervention, normal language, social, and cognitive development is possible.

In March of 1993, the National Institutes of Health (NIH) issued a consensus statement regarding the early identification of hearing impairment in infants and young children. They recommended the "screening of all
newborns, both high and low risk, for hearing impairment prior to hospital discharge." The conclusions of the NIH are supported by the Joint Committee on Infant Hearing , which represents the American Academy of Pediatrics, the American Academy of Otolaryngology, the American Academy of Audiology, and the American Speech-Language-Hearing Association.

The cost per child identified with congenital hearing loss is about 1/10th the cost per child identified with PKU, hypothyroidism, or sickle cell anemia in metabolic disorder screening programs. Such metabolic disorder screening programs are required in all 50 states. By the time a child with a hearing loss graduates from high school, as much as $421,000 per child can be saved in special education costs if that child is identified early and given appropriate early intervention. These savings will pay for universal hearing screening, detection, and intervention many times over.

Thank you for allowing me to share some information regarding this important issue. Again, I would like to strongly encourage support of the Newborn Infant Hearing Screening Act. If I can provide you with any further information, please do not hesitate to contact me.

Sincerely,

Jane L. Campbell, M.A., C.C.C.
Audiologist
William Newton Memorial Hospital

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