Approved 2/29/88
Date

MINUTES OF THE ~~HOUSE~~ COMMITTEE ON PUBLIC HEALTH AND WELFARE.

The meeting was called to order by Marvin L. Littlejohn, Chairperson at

1:30 ~~a.m./~~p.m. on ~~February 25,~~, 1988 in room 313-S of the Capitol.

All members were present except:

Committee staff present:

Norman Furse, Revisor
Sue Hill, Committee Secretary

Conferees appearing before the committee:

Representative Nancy Brown
Kevin Robertson, Director of Governmental Affairs/Ks. Lodging Assn.
Stephen N. Paige/H. & E/Director Bureau of Food/Drug/Lodging
Carolyn Middendort, R.N., M.N. Ks. State Nurses Association
Ann Rogers, Ks. Association of Nurse Anesthetists
James G. Bridgens, M.D./Pathologist
W. Howard Whiteside, M. D. Neonatology, Wichita
Carrie Sheehan, Western Regional Director/ SIDS
David DeJong/ Ks. Society of Pathologists
Verla Britton, President Ks. Chapter SIDS
Debbie Elwick
Brenda Kehler
Neil Leverenz
Debbie Wells
Rita Ryan, H. & E./ Maternal Child Health Director

Chair called meeting to order and welcomed all the nurses and students to our meeting this date. He recognized "Nurses Day at the Capitol", and hoped they would find our meeting interesting. He thanked them for the nice lunch they had sent to he and Rep. Branson in their absence at scheduled luncheon.

Chair drew attention to hearings.

Hearings began on HB 2901:

Representative Brown presented hand-out, (Attachment No. 1). She explained two conferees who were scheduled to appear are ill and will not be able to give testimony. It was these two persons who requested the bill be introduced, i.e., Mr. Rosenthal and Mr. Murphy. She stated the reasons for the bill are obvious, smoke detectors save lives. If an individual cannot hear the beep of the smoke detector, they are unaware of the danger around them. The smoke detector was demonstrated. She stated those hearing impaired individuals become acutely aware of the flashing light or vibrations from the light. This bill was drafted quickly, she said, and noted some clean-up language may be necessary.

She answered questions. Rep. Brown also called attention to (Attachment No.2), Mr. Bill Fansler's printed text. (He was conferee at February 24th meeting.)

Mr. Ed Redmon, State Fire Marshall's Office had demonstrated the portable smoke detector during Rep. Brown's remarks. He explained this can be used with a regular table light. There is also a strobe

Hearings continued on HB 2901:Mr. Redmon continued,

light that is brighter, but considered fairly expensive. He answered questions, i.e., yes, many use this device in their own homes; cost is about $95.00 for one demonstrated here today; some states require a hotel must equip one out of every 50 rooms with this device; there are such devices that can be placed under the pillow or under the mattress that will vibrate when smoke is detected, but the light detector is considered the most effective.

Mr. Robertson, Kansas Lodging Association, (Attachment No.3) stating their group takes no formal position on HB 2901, however, they do accept responsibility of providing their guests with greatest amount of safety when they may be threatened by fire. They approve of language that gives the hotel operator a choice on how to comply with the law. Small hotels could offer lowest level rooms rather than purchase special detectors. They certainly agree with the "upon request" provision. He had spoken to Fire Marshall prior to todays meeting and had other concerns answered to his satisfaction.

Mr. Stephen Paige, Department of Bureau of Food/Drug/Lodging, Health and Environment, (Attachment No.4), stated their Department supports passage of HB 2901. Data indicates 675 lodging facilities licensed in 1987. It is unknown how many of those facilities have multiple floors. Determining compliance of requirements in HB 2901, regular inspections (already done), will give needed information and can be done without any additional expense to their department. Preventing injury or loss of live is most important, and they agree with the language in bill as it now appears.

Hearings closed on HB 2901.

Hearings began on HB 2655:Chairman called attention to a letter provided (Attachment No.5), from Dr. Lois Scibetta, Executive Administrator of Kansas State Board of Nursing. In Dr. Scibettas' absence, Chair read letter to members. Basically their Board did approve regulations recommended by the Registered Nurse Anesthetist Advisory Council.

Chairman noted to members reasons for this bill request.

Ann Rogers, Ks. Association of Nurse Anesthetists (Attachment No.6) stated their Advisory Council did request that Masters level programs be minimum level since this will be the national standard by 1992. This is not an attempt to limit other schools from starting. She noted recommended re-wording in language by changing "masters level" to "baccalaureate level". She explained rationale. She answered questions.

Carolyn Middendorf, Kansas Nurses Association, (Attachment No.7) stated HB 2655 simply does not allow the State Board of Nursing to require a masters level nurse anesthesia program in their approval process for programs. A baccalaureate in nursing is not required and an R.N. with a baccalaureate degree in another field may be accepted. A goal set by the National Association of Nurse Anesthetists is that by 1998 all nurse anesthesia programs will be at the Masters Level. Currently the KU school of Nurse Anesthesia is the thrid largest program in the country. She answered questions.

Hearings continued on HB 2655---

Mrs. Middendorf continued:
i.e., yes, we realize there is a shortage of nurses and nurse anesthetists, but we feel they need more education because of all the advance technology today. Three years isn't enough. We aren't criticizing. It is necessary to have a broader base of education.

Hearings closed on HB 2655:

Hearings began on HB 2777:

Representative Cribbs stated he had been approached by members of Sudden Infant Death Syndrome, (SIDS) who requested introduction of this bill in their behalf. He yielded to the conferees.

Representative Amos introduced Dr. James Bridgens, Forensic Pathologist gave hand-out to members, (Attachment No.8-A,8-B). He gave background of this tragic occurrence in death of infants. He cited statistics, spoke of the trauma that is caused to parents, siblings, medical community. He suggested numerous changes in language of HB 2777, in lines 29,39,58,64,76,79,85. He stated, there are qualified pathologists available to all areas of the state so there is no need for autopsies to be performed by individuals with little or no training. Autopsies to be performed on these small persons need to be done by experienced and skilled pathologists. If done by an individual with less experience little subtle findings might be overlooked. He noted the pituitary collection program has been discontinued by NIH. He recommended further changes, Statutes KSA 1975, 19-1030, KSA 19-1031, KSA 1975 Supp. 19-1033. He encouraged passage of HB 2777, and noted these other changes need to be made and perhaps this would be a good time. He answered questions, yes, there are many possible causes for SIDS, literally 100 causes; yes, it is vital we need to make sure the child had not been abused, and the autopsy is the only way to tell us; yes there have been a great number of studies done trying to evaluate autopsies so as to determine cause of SIDS.

Dr. Howard Whiteside, (Attachment No.9) gave factual information that does not appear in printed text. He noted there are certain maternal factors that can contribute to SIDS, i.e., young age of mother, short periods of time between pregnancies; smoking; drug use and abuse/ smoking 5 or more cigarettes a day; prematurity; small birth rate babies; black and other minorities; lung conditions in infant; and other causes can make babies born into a high risk group. There are already 75% cases that are being autopsied, but 100% is needed. We can continue to learn from this, and perhaps help others. Autopsy needs to be performed by a skilled and experienced pathologist. SIDS deaths have increased. He answered numerous questions.

Carrie Sheehan, Regional Director of National SIDS Foundation, Seattle, Washington gave hand-out, (Attachment No. 10). She is the mother of a child that died of SIDS 33 years ago. She related some personal experiences and has worked with the SIDS Foundation since this tragedy. There are 29 states with some type of SIDS legislation. Yes, to mandate an autopsy is necessary,it is the only piece of mind that a family can have. There are 20 people affected after a SIDS death. family members, medical community; daycare workers, and others. Yes, it is cost effective legislation. Hopefully we will soon learn from autopsy information what causes this trauma. She urged for support of HB 2777.

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,

room 313-S, Statehouse, at 1:30 ~~a.m.~~/p.m. on February 25, 19 88

Hearings continued on HB 2777:---
Dr. David DeJong, Pathologist from Wichita, gave hand-out, (Attachment No. 11). The present form of HB 2777 is good. There should be a committee of pathologists and pediatricians to monitor and evaluate autopsy results on a regular basis. Only qualified individuals should perform the examinations, and such examinations (autopsies) completed according to appropriate protocol. He made recommendations to further expand the bill, i.e., sunset clause of perhaps 6 years; clarify language so it does not direct coroners to perform post mortem exams, but to ensure they are performed by a qualified person; add the word "liveborn" in line 37; and re-evaluate lines 56 to 58 since they are inappropriate and medically incorrect; fee of $1000 is more realistic than $500. He answered questions.

Verla Britton, President, Ks. Chapter SIDS, (Attachment No. 12), stated a mandatory autopsy law for Kansas would mean we could get closer to discovering the cause or causes of SIDS and eventually put an end to this silent killer.

Debbie Elwick, parent of a SIDS child. She related her personal story, and of her work as a nurse dealing with parents who must too often deal with this trauma. She spoke of the frustration that comes from not knowing what causes these deaths in infants, frustration of parents, physicians, other loved ones. Mandatory autopsies will help them learn more. She is satisfied the right thing was done to have an autopsy done at the death of her daughter Annie. Presently counties pay for autopsies, and large counties do not feel this is a hardship, but those smaller counties, funds are not as available so to have the state pay for such autopsies will help. She urged for favorable consideration of HB 2777. (Attachment No.13).

Brenda Kehler, (Attachment No.14), parent of a SIDS child. They elected at the time of their son's death not to have an autopsy performed, saying they didn't want "that" done to their child. Since then, they have wondered if there had not been something else that might have caused Christopher's death. They will never know. They are sorry they did not consent to the autopsy. They now realize the value to self and others from the information that can be learned by having an autopsy report.

Neil Leverance, (Attachment No. 15) related their personal experiences at the death of their son Jason, the choice of autopsy was theirs, they declined. Now they realize there were questions they needed answered, but it is too late. The value of information from a SIDS death can help both parents and research. They will never know if their son truly died of SIDS. They support mandatory autopsies in the case of a SIDS related death.

Debra Wells, (Attachment No. 16), gave some personal remarks in regard to the tragic death of her 6½ week old son in 1980. She urged language be placed in HB 2777 that would speak to having the autopsy report made available to parents of the child in a timely manner. They could not obtain a report until 6 weeks after their child died, and then only after many many phone calls of inquiry. She supports mandatory autopsies. Autopsies are important because the care-giving staff must be above reproach as well as the parents, and information learned can perhaps help discover answers to all the WHYs.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,

room 313-S, Statehouse, at 1:30 ~~a.m.~~/p.m. on February 25, 1988

Hearings continued on HB 2777----
Rita Ryan, Coordinator, Health Services for Mothers and Children, Department of Health and Environment, (Attachment No. 17), said perhaps the most tragic of all infant deaths are those attributed to SIDS. Providing access to an autopsy will help determine cause of death and to rule out brain hemmorhage, viral causes, reactions to an immunization, and others. Autopsy can conclusively determine the cause of death where SIDS is suspected. They support HB 2777, however, do recommend that new Section 2 bill be amended to include; 1) autopsies be done by competent pathologist; 2) phrase "under two years of age" be changed to "in the first year of life"; 3) copy of report be forwarded to Department of Health and Environment; 4) Department of Health and Environment be the payor of last resort for these autopsies.

Chairman thanked all conferees for their testimony, recognizing that it was most difficult for many. Members of this committee commend them for their testimony and for their courage.

Chair announced there will be a need to request some of our bills be re-referred to Appropriations so they can be returned to this committee at a later date to have appropriate action taken on them.

Meeting adjourned 3:25 p.m.

GUEST REGISTER

HOUSE

PUBLIC HEALTH AND WELFARE COMMITTEE

Date 2-25-88

| NAME | ORGANIZATION | ADDRESS |
|---|---|---|
| Vonda Donovan | St. Mary of the Plains College | Wichita KS |
| Pamela Smith | Butler College Nursing | Wath, Ks |
| Gretchen Underwood BSN RN | Wichita State Univ. | Wichita, Ks |
| Mary Koerner | KSNA | Andover, Ks. |
| Jan Kiorchini | UKSM-W Health Care Nursing | Wichita |
| Sandra Taylor BCCC student nurse | BCCC 631 N Chautauqua | Wichita KS 67214 |
| Ronda Pederson RN | Wichita State University | Wichita Ks |
| Doreen Graber RN | Hutchinson Hospital Corp. | Hutchinson, Ks 67502 |
| Dorothy Asta RN | Retired OB area | Hutchinson Ks |
| Carol Starbird | Washburn University | Hoyt, Ks |
| Galen Hollenbaugh | " " | Topeka |
| Erin Monroe | Washburn University | Topeka, Ks. |
| KEITH R LONGIS | CHRISTIAN SCIENCE COMMITTEE ON PUBLICATION FOR KANSAS | TOPEKA |
| SHELLY LIST KUSN | Univ. of KS School of Nursing | K.C., KS. |
| Norma Bauer | NURSING INSTRUCTOR BUTLER CO. COMM. COLLEGE | EL DORADO, KS. |
| Ethel Henderson | Nurse Clinician (RN) | Kingman, KS. |
| Kerrin Hake | Cloud Co Comm College | Concordia, KS |
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GUEST REGISTER

HOUSE

PUBLIC HEALTH AND WELFARE COMMITTEE

Date 2/25/88

| NAME | ORGANIZATION | ADDRESS |
|---|---|---|
| Debbie Himpel | Washburn Nsg | Topeka |
| Lori Edwards | Washburn Nsg | Topeka |
| Rick Hoffmeister | Washburn University | Topeka, Ks |
| Nancy L Herzog | Washburn School of Nursing | Topeka |
| Sue Ann Schamberger | Fort Hays School of Nursing | Hays |
| Mary E. Meyer | (Ks Ass. of Nurs. Stud) K.A.N.S., FHSU Nurg. | Hays |
| Regina Hopwood, RNBSN | KNSA-WSU Graduate Program | Rt 1 Box 85M Milford, Ks 66514 |
| Deese Jackson RN, BSN | Wichita State U. - Graduate Program | Topeka, Ks |
| Candace Byrne | Instructor - Newman Hospital Sch of Nsg | 2507 Monterey Dr. Emporia Ks 6680 |
| Sue Owens | Fort Hays State Nursing | Hays |
| Tracy Penson | Fort Hays State Nursing | Hays |
| Belinda Warner | Fort Hays State Nursing | Hays |
| Karen Cole | Fort Hays State School Nsg | Hays |
| Mary Huling | Mid American Nazarene Coll | Olathe |
| Angela East | Mid America Nazarene College | 303 S. Blake St. Olathe, Ks. 66061 |
| Audra Brungardt | Fort Hays State School of Nursing | Hays |
| Lysa Larkin | Fort Hays State School of Nsg | Hays, KS 67601 |
| H. Wessel RN | KSNA | 900 N. Maple, Frankfort, KS 66427 |
| Jan Bergman | KSNA | 1011 Nemaha, Seneca, Ks. 66538 |
| Sharon Stewart | Fort Hays State School of Nursing | Hays |
| Teri Collins | Fort Hays St. School of Nursing | Hays, KS 67601 |
| Linda Bonnel | KSNA | Topeka |
| Blynn August | Anderson Coulee + Assoc | Wichita |

GUEST REGISTER

HOUSE

PUBLIC HEALTH AND WELFARE COMMITTEE

Date_____

| NAME | ORGANIZATION | ADDRESS |
|---|---|---|
| Judy Stenfors | Dodge City Com. Colle Nsg | 1502 Ave B Dodge City KS |
| Eugenia Kiser | Dodge City Com College NSG | 1310 Central Apt #1 Dodg City Ks |
| Linda Tukenskey | KS Assn of 4-H Agcy. | Lawrence |
| Jodi Hollis | KSNA | RR2 Meriden, Ks 66512 |
| Joann Flower | KSNA | RR2, Box 2, Oskaloosa 66066 |
| Lenita McClintock | Cloud County Com College Nsg | 2401 Simmons Salina KS 67401 |
| Judi Fiskeng | Cloud County Comm College Nsg | 1509 State Concordia KS 66901 |
| Randall Mitchell | Butler County Com College | El Dorado Kansas |
| Brenda Carver | Butler Comm. College | Wichita, Kansas |
| Kathy Long | Butler County Comm. College | El Dorado, KS |
| Judy Carter | Butler County Comm College | El Dorado, KS |
| Ada Sayer | Butler County Community College | El Dorado KS |
| Deborah Jones | Butler County C. College | Eldorado Kansas |
| Mary Engelman | Butler County Comm. College | El Dorado, Ks |
| Sheryl LaForge | Butler Co. Comm. College | El Dorado, KS |
| Donna Rungeisen | BCCC | El Dorado, Ks. |
| Mary Fitzpatrick | WSU - Masters Nursing Student | RR1 - Box 31A Independence, KS |
| DeLynn Bohnenblust | WSU - Masters Nursing Student | Box 216 Altamont, KS 67330 |
| Carrie Olsen | Washburn University | Topeka, KS |
| Michelle Koch | Washburn University | Topeka, KS |
| Jamie Vincent | Washburn University | Topeka, Ks. |
| Diane Trevino | Washburn Nursing | 7235 SE 61st Tecumseh |
| Denise Bredow | Washburn University | Topeka KS |

GUEST REGISTER

HOUSE

PUBLIC HEALTH AND WELFARE COMMITTEE

Date 2/25/88

| NAME | ORGANIZATION | ADDRESS |
|---|---|---|
| Michele Dalton | Washburn Univ. - KSNA | Topeka |
| Kellee Wilson | FHSU School of Nurs | Hays. |
| Beth Bellinger | FHSU School of Nurs | Hays |
| Michele Jeannin | WU - (KSNA) | Leavenworth |
| Janet Eagan | Washburn University | Topeka, KS |
| Esther Oppliger | Wichita State University | Wichita, KS |
| Freda Comfield | WSU (KSNA) | Wichita, KS |
| Cindra Nusbaum | WSU (KSNA) | Wichita, Ks |
| Debra S. Barrett BSN RNC | WSU (KSNA) | 1338 Sunset Ct. Wichita KS |
| GINA L. STADIG | WSU (KSNA) | 1201 S. PAIGE #302 WICHITA 67207 |
| Bonita Jensen | Hadley Regional Med Center KSNA | 201 East 7th Hays, KS 67601 |
| Isabel Daniel | Hadley Reg. Med. Center KSNA | 201 E. 7th, Hays, Ks. |
| Cheryl A. Miel | Hadley Regional Med Center | Rt 2 Box 2 Ellis KS 67637 |
| Nancy Blume RN, MS | Nursing Dept Wichita State University | Wichita, Ks. |
| Debra Ortmeier | KU School of Nursing | 6802 W. 50th Place Mission, KS 66202 |
| Raj R. BAJAJ | BCCCN School of WICHITA | 624 N. PINE CREST WICHITA |
| Peggy J. Erickson | KSNA President | 820 Quincy Topeka Ks. 67200 |
| Melinda K. Smith | El Dorado, KS BCCCNS | 344 N. Bluff Wichita Ks. |
| Rosalind F. Allen | Butler Comm. College | 1117 N. Poplar Wichita Ks |
| Doina Gombos | Butler County College | 6602 E. Harry # 12 10 Wichita Ks |
| S Jogl Chgr | St mary of Plain College stormont Vail Campus | 1000 SW 10th Topeka 66604 |
| Jeanette Whitsitt | Phillips County Hospital | Phillipsburg, Ks |
| Delora Donovan | KANA | Wichita, |

STATE OF KANSAS

NANCY BROWN
REPRESENTATIVE, 27TH DISTRICT
15429 OVERBROOK LANE
STANLEY, KANSAS 66224-9744

TOPEKA

COMMITTEE ASSIGNMENTS
MEMBER GOVERNMENTAL ORGANIZATION
INSURANCE
TRANSPORTATION

HOUSE OF
REPRESENTATIVES

TO: Public Health and Welfare

DATE: February 24, 1988

RE: Testimony on House Bill No. 2901

Mr. Chairman and members of Public Health and Welfare, I appreciate the opportunity to testify before you today on behalf of several individuals who cannot be here today. Mr. Fred Murphy, President of the Kansas Association for the Deaf, was recently released from the hospital and is recuperating at home. Mr. David Rosenthal, Executive Director for the Kansas Commission of the Deaf, is ill today and cannot be here.

This bill was introduced by request of Mr. Murphy and Mr. Rosenthal on behalf of the thousands of deaf and hearing impaired citizens of the state of Kansas. To me, the reasons for the bill are obvious - smoke detectors save lives. If an individual cannot hear the beep of the detector, they obviously are unaware of the dangers of smoke and fire.

Yesterday during the briefing there was a question about the detector for deaf and hearing impaired. Let me assure you that they do work and, in fact, such devices are similar to those used by parents who need to hear crying children during the night. While they cannot hear the sounds of a crying child, or the beep of a smoke detector, they become acutely aware of flashing lights or vibrations. In a few minutes, John Coslett, of the State Fire Marshall's Office will demonstrate the devices for you.

The bill was drafted quickly and there may be a few recommendations for technical changes which would be appreciated, as long as they address the purpose of the bill.

Thank you.

Attm #1
2-25-8
DA/tcw

House Bill 2901

I am Bill Fansler, second vice president of Kansas Association of the Deaf and a former board member of Kansas Commission for the Deaf and Hearing Impaired. I am representing KCDHI on behalf of David Rosenthal, executive director who was unable to attend the hearing on Wednesday, Feb. 24.

I am in favor of House Bill 2901 regarding the placement of visual smoke detector in hotel and motel rooms in Kansas for the use of deaf and hearing impaired guests who request such system.

Regular smoke detector placed in each room without flashing light signal is not helpful or even safe for such guests, simply because they cannot hear the alarm going off. Thus, the deaf and hearing impaired are being discriminated in terms of fire safety.

There are smoke detectors with flashing light hook up on the market. They can be ordered from several reliable sources.

There is a wireless adapter hooked up to a lamp or a strobe light positioned toward a sleeper's head. When a smoke detector, already located in a room goes off, the adapter activites the light, waking the heaviest sleeper up.

Hotel and motel people can "loan" such system to the deaf and hearing impaired guest, who must be made aware of its availability. Better yet, the visual warning system could already be placed in the room.

Safety from smoke and fire is number one concern of not only the deaf and hearing impaired guests, but of the elderly guests who lose their hearing. Wearing hearing aids while sleeping in bed is not a good idea and it is not comfortable at all.

Several years ago there was a fire in a large Chicago hotel where several deaf children from Illinois School for the Deaf were killed by smoke. They were not aware of what happened and were overcome by smoke.

There have been state and city laws requiring hotels and motels to place visual warning system since then. We, the deaf and hearing impaired people want to see Kansas pass this bill to protect, not only the deaf and hearing, but ALL people who are guests in hotels and motels in our state.

Finally, it would be a good public relations for Kansas hotel and motel industry who cares for their guests in safety and comfort. Also those running the hotels and motels will have peace of minds, when visual smoke detectors are protecting them.

A life saved in the event of a fire is a life SAVED by having a visual warning system placed in designated rooms. Every person has a right to have a life on earth and please do not let a tragedy happen if a life is lost.

On behalf of the deaf and hearing impaired, I would appreciate the bill being passed favorably by your committee and be sent to full House for favorable consideration. Thank you for reading this.

Bill Fansler

Bill Fansler

Attm #2
2-25-8

HB 2972

In reference to House Bill 2972 which allows guide dog trainers and hearing dog trainers, I am supporting it , providing that the line "guide dog trainer" be left intact.

Hearing dogs, in reference to be allowed certain places with their owners has been amended to guide dog bill 4 years ago. So both types of trained dogs are included.

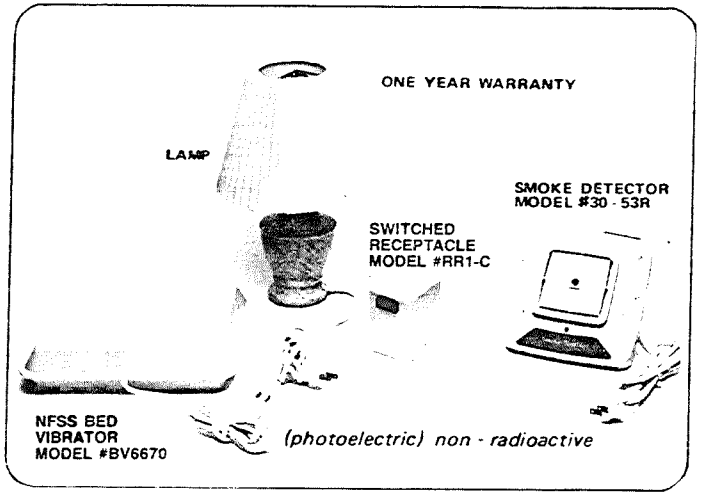
It would be unfair if guide dog trainer be discriminated in term of giving dogs real time training if it is taken out of the bill. So it is necessary to leave the hearing provision intact in HB 2972.

Thank you,

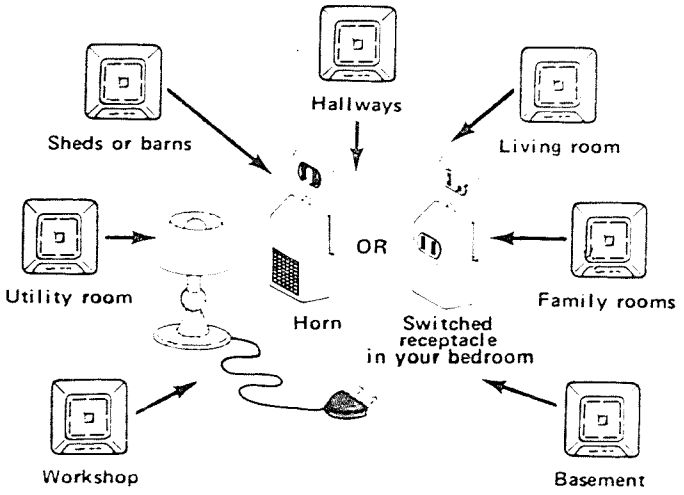
Bill Fansler, 2nd vice-president
Kansas Association of the Deaf
1940 Bowman Court,
Topeka, Kansas 66604

Bill Fansler

## WHAT IT IS AND HOW IT WORKS.

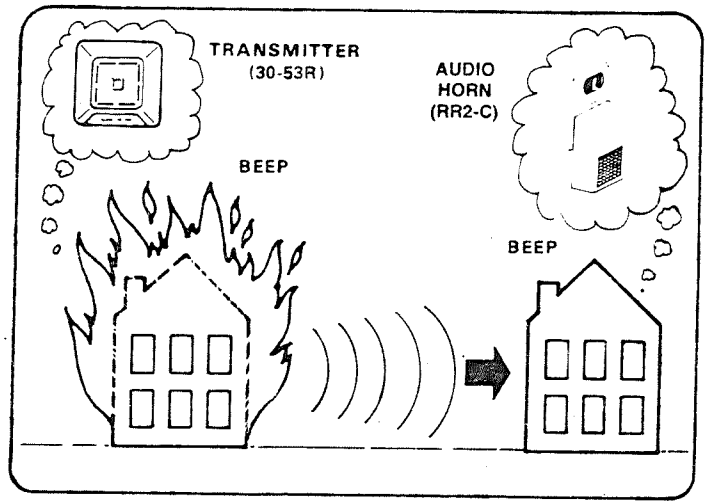



*The wireless smoke detector has a built-in wireless transmitter and requires it only to be plugged into a 120 volt power source in the house. This transmitter will turn on flashing lights (lamps) at the switched receptacle after sensing the rising smoke from a fire. The flashing lights will stay on and the horn from the detector transmitter will continue as long as it senses smoke. When smoke clears from the room the transmitter reverts to standby and the flashing lights and alarm will stop. Use as many detector transmitters as necessary to protect your home. NO ELECTRICIAN REQUIRED.



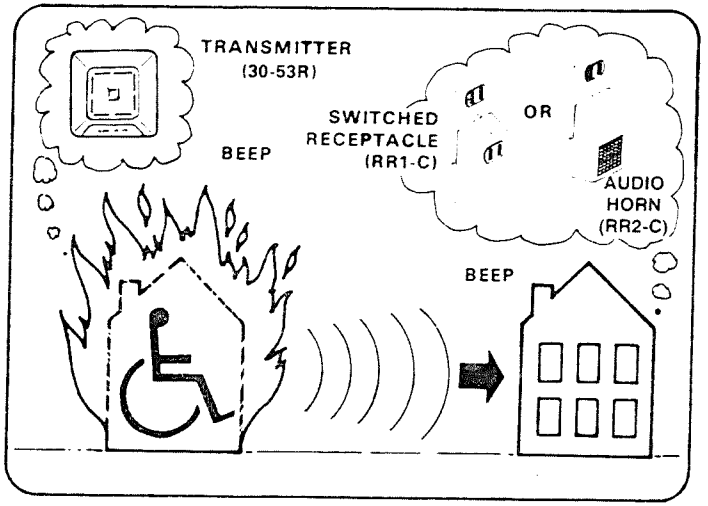

TE: For those who are "heavy sleepers" may not be awakened by flashing lights, vibrators (under bed pillows) can be connected to the switched receptacles.






## WHILE YOU ARE AWAY OR ON VACATION

The audio horn receiver can even plugged in at your neighbor's home to monitor detector transmitters installed in your home. If there's a fire in your home, the detector transmitter will sound and send a signal to the audio horn receiver in your neighbor's home. This unique system can protect your home from fire—even when you're not there to see or hear the alarm yourself. Relax in safety and enjoy your vacation.



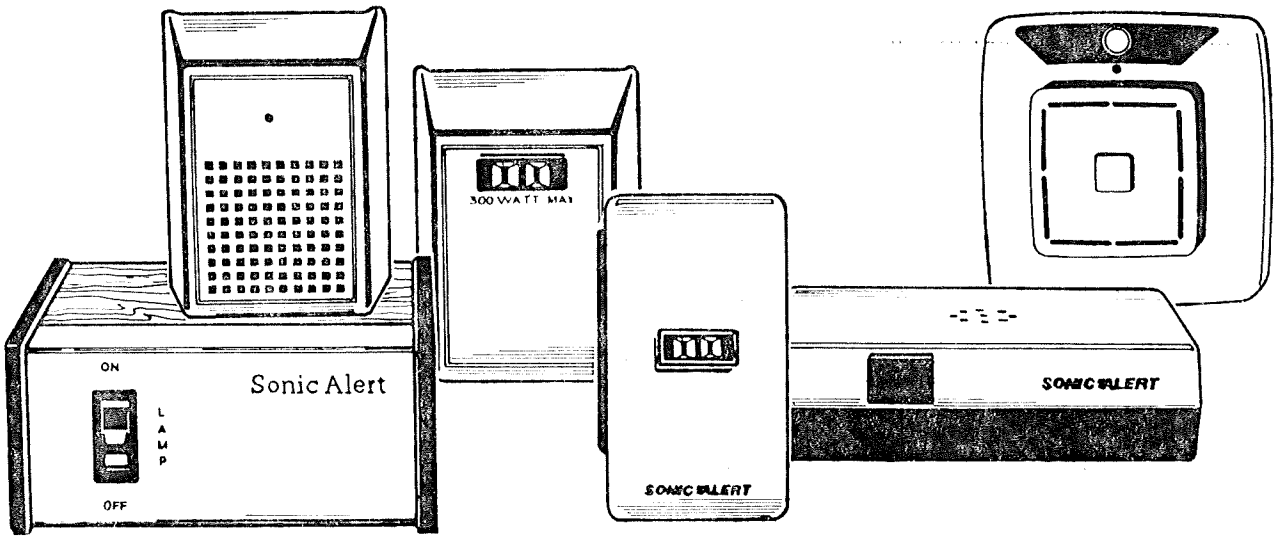

## FOR BLIND AND DISABLED INDIVIDUALS

Save the lives of your blind and/or disabled neighbors by getting them out of their homes in time to escape fire and smoke.

# LET

# SONIC ALERT

# HEAR FOR YOU!




# WE TURN SOUND INTO LIGHT!

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## DESIGNED FOR COMFORT AND SAFETY!

KANSAS LODGING ASSOCIATION

STATEMENT

TO: House Committee on Public Health & Welfare

FROM: Kevin Robertson, Director of Governmental Affairs

DATE: February 24, 1988

RE: HB-2901

Mr. Chairman and members of the committee my name is Kevin Robertson, Director of Governmental Affairs for Barbee & Associates. Today I am appearing before you on behalf of the Kansas Lodging Association's approximately 200 hotel and motel properties ranging in size from one to 400 rooms.

The Kansas Lodging Association (KLA) has no formal position on HB-2901, a bill requiring hotels to either provide portable smoke detectors or a lowest level room to their hearing impaired guests upon request. Though KLA is generally opposed to legislation which imposes increased requirements on the lodging industry, in this case our members accept the responsibility of providing their guests with the greatest amount of safety when they may be threatened by fire.

There are several elements of this bill which the Lodging Association sees as most favorable to our members. First, we like the provision in the bill which gives the hotelier a choice on how to comply with the law. Hotels which do not feel they can afford these portable smoke detectors at this time may simply supply their hearing impaired guests with a lowest level room. Further, with this provision in the bill, all of our smaller, one level properties would be automatically in compliance with the law. Second, many of our larger property members do not have ground level rooms and this is adequately addressed by allowing the hotel to provide rooms to hearing impaired guests on the lowest floor where guest rooms are located. Though we expect many of our larger hotels will purchase portable smoke detectors for the hearing impaired, once again it gives them an alternative if they do not feel they can immediately afford such devices. Third, KLA agrees with the "upon request" provision of the bill. We do not feel it would be possible for a hotel to recognize all hearing impaired guests, and several may not want such special treatment.

atchm # 3
2-25-8
PH & W

810 Merchants Tower • 800 Jackson • Topeka, Kansas 66612 • (913) 233-9344

The Kansas Lodging Association does have several questions about HB-2901 which I hope can be answered here today:

1) How available are such smoke detectors? Where can they be purchased? How much do they cost?

2) Would hotels which opt not to purchase these smoke detectors be required to leave a lower level room vacant all day and evening in anticipation of a hearing impaired guest?

3) In several two or more story hotels ground level rooms are often $2.00 or so higher for all guests because they are more convenient, therefore, guests are willing to pay a higher rate for them. Would this be allowed if a hearing impaired guest requested such a ground level room?

4) Hypothetically, what if a hotel has one portable smoke detector available for a hearing impaired guest which is currently in use, and another guest requests a smoke detector or a lower level room. Though the hotel may have rooms available, there are no lowest level rooms available. Would this hotel be in violation of the law?

Thank you for allowing me to address the Kansas Lodging Association's views on HB-2901. I will now attempt to answer any questions you may have.

STATE OF KANSAS

DEPARTMENT OF HEALTH AND ENVIRONMENT
*Forbes Field*
*Topeka, Kansas 66620-0001*
*Phone (913) 296-1500*

Mike Hayden, *Governor*

Stanley C. Grant, Ph.D., *Secretary*
Gary K. Hulett, Ph.D., *Under Secretary*

# TESTIMONY PRESENTED TO

# HOUSE PUBLIC HEALTH AND WELFARE COMMITTEE

# BY

# THE KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

## House Bill 2901

Passage of House Bill 2901 would amend the Kansas Food Service and Lodging Act requiring hotels to provide portable visual warning smoke detectors upon request for hearing impaired guests. In lieu of such smoke detectors guests may be provided rooms on the lowest floor of the lodging facility.

Records of the Kansas Department of Health and Environment indicate a total of 675 lodging facilities were licensed in 1987. It is unknown how many of those licensed facilities have multiple floors. Determining compliance with the provisions of House Bill 2901 can be included as part of routine inspections without additional staff or operating funds.

Considering the potential for preventing injury or loss of life, we support passage of House Bill 2901.

Presented by:

Stephen N. Paige
Director
Bureau of Food, Drug and Lodging
February 24, 1988

Attm #4
2-25-88
pp&w

# Kansas State Board of Nursing

Landon State Office Building
900 S.W. Jackson, Rm. 551
Topeka, Kansas 66612-1256
913-296-4929

Lois Rich Scibetta, Ph.D., R.N.
Executive Administrator

Bonnie Howard, R.N., M.A.
Practice Specialist

Janette Pucci, R.N., M.S.N.
Educational Specialist

M E M O R A N D U M

TO: Representative Marvin Littlejohn, Chairman
and Members of the House Public Health and Welfare Committee

FROM: Dr. Lois R. Scibetta, Executive Administrator

RE: House Bill 2655

DATE: February 19, 1988

Thank you, Mr. Chairman, for the opportunity to provide written testimony regarding HB 2655.

As you know, HB 2655 modifies temporary regulations now in place for Registered Nurse Anesthetists. The recommendation for the masters level proviso came from the Registered Nurse Anesthetist Advisory Council, which made recommendations to the Board of Nursing for nurse anesthetist regulations. The Board did approve the regulations, based upon these recommendations. It was our understanding that all future programs had to be at the masters level in order to gain national approval.

The Board has not been polled on the change suggested, however we felt the Committee would like to know why this section was included.

We appreciate the opportunity to comment.

LRS:adr

Attm. #5
2-25-8
PH+Wed

LICENSURE REGULATION PUBLIC BOARD OF NURSING TRUST LEGISLATION EDUCATION

# KANSAS ASSOCIATION OF NURSE ANESTHETISTS

February 25, 1988

HOUSE PUBLIC HEALTH AND WELFARE COMMITTEE

HB 2655 - concerning masters level requirement for nurse anesthesia schools in Kansas.

Representative Littlejohn and members of the committee I am Ann Rogers a Registered Nurse Anesthetist and I represent the Kansas Association of Nurse Anesthetists.

HB 2655 would amend the RNA authorization statute to specify that the board of nursing cannot require schools of anesthesia to be a masters level program.

The nurse anesthetist advisory council to the board did request that masters level programs be minimum level as this will be the national standard by 1992. This was not an attempt to limit other schools from starting. The council also recommended in the Public hearing on the rules and regulations that the masters level be dropped if it would be regarded by the board as an entry level into practice. The national and state shortage of RN's and RNA's has become so criticial that the Kansas Association of Nurse Anesthetists requests that subsection (b) be reworded as follows: Schools of nurse anesthesia accredited or approved by the board under this section may offer, but shall not be required to offer, a baccalaureate level degree program in nurse anesthesia. The major reason for the KANA to recommend this change is that if the board would require all new graduates and all RNA's coming into the state to be master's level prepared than very few would meet the qualification. The majority of practicing nurse anesthetists in the United States are certificate school graduates, which merely states the school met minimum accrediting standards for that time. Most nurse anesthetists do not have a B.S. or M.S. and since K.U. cannot fill all the empty nurse anesthetist positions in Kansas every year a masters entry level would impose a great hardship to the health care system in Kansas.

I will be happy to answer any questions the committee may have and thank you for the opportunity to testify.

Attm. #6
2-25-88
2 pgs

# KSNA
the voice of Nursing in Kansas

FOR FURTHER INFORMATION CONTACT:

TERRI ROBERTS, J.D., R.N.
EXECUTIVE DIRECTOR
KANSAS STATE NURSES' ASSOCIATION
820 QUINCY, SUITE 520
TOPEKA, KANSAS 66612
PHONE: (913) 233-8638

H.B. 2655 - APPROVED COURSES OF STUDY IN NURSE ANESTHESIA

Representative Littlejohn, and members of the House Public Health and Welfare Committee, my name is Carolyn Middendorf, R.N., M.N., and I am presently a nursing instructor at Washburn University School of Nursing. I have been in the field of nursing for fifteen years and am currently the Legislative Chairperson for the Kansas State Nurses' Association.

KSNA supports H.B. 2655 proposed by the Joint Committee on Administrative Rules and Regulations.

The bill simply does not allow the Kansas State Board of Nursing to require a masters level nurse anesthesia program in their approval process for programs.

Currently only 47% of the schools in the U.S. are at the Masters level, with 15% at the baccalaureate and 38% are at the certificate level. The KU Nurse Anesthesia Program just recently converted to a Masters level program. Currently all nurse anesthesia programs in the U.S. require a baccalaureate degree to enter the program. A baccalaureate in nursing is not required and an R.N. with a baccalaureate degree in another field may be accepted. There is a goal set by the National Association of Nurse Anesthetists that by 1998 all nurse anesthesia programs will be at the Masters Level. Currently the KU School of Nurse Anesthesia is the third largest program in the country.

Thank you.

Attm #7
2-25-8
P+HW

**James G. Bridgens, M.D.**
Forensic Pathology • Medical-Legal Consultation

11 Feb 88

The Honorable Eugene P. Amos
5925 Bluejacket
Shawnee, KS 66203

Re: HB 2777

Dear Honorable:

Many thanks for sending me a copy of HB 2777. Perhaps this bill will make it possibile to add a few needed changes to the Coroner's Law.

I would suggest that the following changes be made to HB 2777: (existing verbiage in brackets, suggested changes underlined)

| Line | Suggested Changes |
|---|---|
| 0029 | ...or unusual manner, or when in police custody, jail or penal institution or ... |
| 0039 | ...within this state under circumstances [indicating that death may have been caused by sudden infant death syndrome] in which death is not anticipated or is.... |
| 0058 | ...syndrome unless an autopsy [is] has been performed. |
| 0064 | ...such autopsy shall be [made] performed by [the coroner or by such] a qualified pathologist [or other licensed physician] as may be designated by the coroner [for the purpose]. A [person] pathologist performing an autopsy.... |
| 0076 | (b) The [person] pathologist performing the autopsy... |
| 0079 | ...death. [Unless the next of kin of the decedent specifically prohibits the retention of the pituitary gland of the decedent, the person performing the autopsy may remove and retain the pituitary gland of the decedent for use in scientific investigation, research, teaching and the practice of medicine.] |
| 0085 | ...autopsy and findings of the [person] pathologist [making] performing such autopsy... |

Attm. # 8-A
2-25-88
PH&CW

1025 Huntington Road • Kansas City, MO 64113 • 816 / 363-1123 • Answering Service: 913 / 677-7615

The following explainations are the basis of my suggested changes:

1. Individuals dying while in police custody, jail or penal institutions need to be evaluated by an independent outside specialist to define the cause of death and relate the findings to the circumstances of death. This may help overcome spurious charges of police brutality, neglect, etc.

2. Not all infant deaths appear to be Sudden Infant Death Syndrome at the outset. Only by the elimination of natural or other death causes can such a diagnosis be determined. Death can be anticipated in those infants known to have congenital defects or existing disease processes. Without these defects or disease, the death may be due to a contagious disease, homicide, or accident as well as SIDS. Autopsy findings must be correlated with the circumstances of the death.

3. The State of Kansas now has qualified pathologists available to all areas. There is no need for autopsies to be performed by individuals with little or no training or competence. In 1988, all coroner's autopsies should be performed by a trained, qualified pathologist--those physicians with little or no experience and training may miss the subtle changes encountered in natural disease or violent death. (Not infrequently, their examination is considerably less than should be done or pertinent evidence, such as bite marks, are glossed over.)

4. All deaths in police custody, jail or penal institutions should be examined by a pathologist. At the present time the Coroner's Law does not specifically give the coroner jurisdiction over deaths occurring in state institutions. Postmortem examination is essential to document the cause of death and avoid potential litigation charging brutality or neglect by those responsible for the care of such inmates.

5. Currently, the pituitary collection program has been discontinued by NIH, as a number of recipients of human growth hormone have succumbed to a virus disease thought to have been transmitted by the extract. The NIH has promulgated regulations prohibiting the clinical use of human growth hormone and as a result, the demand has greatly diminished. Glands for research and laboratory use are still collected from those agencies capable of supplying large numbers--such as the medical examiner offices of Dallas, Detroit, Los Angeles, etc. There is no single source in Kanses to economically justify participation in this program. (Incidentally, as a member of the NIH pituitary committee, I can assure you that the needs for laboratory and research purposes is being adequately met.)

In addition to the above suggested changes, the additional recommendations follow:

KSA 1975 Supp. 19-1030 as amended by Chapt. 124, Sec. 1 of the 1976 Session should be amended to read: (a) The coroner [shall¶ may hold an inquest....

KSA 19-1031 should be amended to include sheriffs, jailers or penal authorities if the changes delineated in line 0029 of the proposed bill are made.

KSA 1975 Supp. 19-1033 should be amended as follows to put a specific time limit on the retention of specimens. The [person] pathologist performing the autopsy shall remove and retain [as long as necessary] for a period of 3 years such specimens as appear to be necessary in the determination of the cause [and circumstances] of death. (Circumstances are documentary, not specimens.)

Many thanks for the opportunity to participate in the input to the changes of this bill and the law. Changes are needed, perhaps now is the time to get them made. Should you have and questions regarding these suggested changes, (or anything else) do not hesitate to contact me. If appropriate, I will make myself available to testify before interested committees

Sincerely,

James G. Bridgens, M.D.

XC: J. Michael Boles, M. D.

SIDS--HB NO. 2777

KANSAS--1986 N = 69; 20.5% OF ALL INFANT DEATHS (N = 337)
--RATE NEARLY DOUBLED SINCE 1980
--INSPITE OF 3.7% DECLINE IN NUMBER LIVE BIRTHS
RATE: NATIONAL 2/1000; KANSAS SHOULD REPORT 80/YR

| YR | N | Rate/ 1000 |
|---|---|---|
| '80 = | 36 | 0.88 |
| '81 = | 50 | 1.21 |
| '83 = | 59 | 1.46 |
| '84 = | 53 | 1.32 |

CAUSE FOR DECREASED NUMBER REPORTED
--LESS AWARENESS?
--POOR REPORTING?
--MORE AUTOPSIES NEEDED?
--DECREASED PUBLIC EMPHASIS?

AUTOPSY EXCLUSIONARY; 15% PRESENT VARIETY OF LETHAL LESIONS/DISEASES

--ACCIDENTAL ASPHYXIA
--OCCULT TRAUMA
--SEPSIS
--PNEUMONIA
--VIRAL INFECTIONS
    --CMV VIRUS
    --MYOCARDITIS
--CONGENITAL DISEASE/ABNORMALITY
--CHILD ABUSE
    --TRAUMA
    --MALNUTRITION

COMPLETE EXAMINATION--ALL VITAL ORGANS, INCL. TRUNK, NECK AND HEAD

--INCLUDES MICROSCOPIC EXAM OF TISSUE SECTIONS
--INCOMPLETE EXAMINATION = MISSED INJURIES/DISEASE

MUST BE PERFORMED BY QUALIFIED PATHOLOGIST
--SUBTLE CHANGES OF TRAUMA/DISEASE EASILY OVERLOOKED
--QUALIFIED INTERPRETATION OF MICROSCOPIC SECTIONS
--CRITICAL CORRELATION OF FINDINGS WITH CIRCUMSTANCES

STATUTE SHOULD INCLUDE REPORTING TO QUALIFIED AGENCY
--COUNTY HEALTH DEPARTMENT
--SIDS GROUP (NONE EXIST AT PRESENT)

--PARENTS NEED SUPPORT AND FOLLOW UP
    --TREMENDOUS EMOTIONAL IMPACT ON PARENTS
    --HIGH LEVEL OF GUILT/ACCUSATION
    --NEED TO KNOW
    --PRESENCE OF FAMILIAL DISEASE

LINE 0039 SHOULD BE MODIFIED TO "IN WHICH DEATH IS NOT ANTICIPATED"
--ELIMINATES KNOWN DISEASE OR CONGENITAL DEFECTS
--SIDS NOT ALWAYS "INDICATED BY CIRCUMSTANCES"

Attm. # 8-B
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ADDITIONAL SUGGESTED CHANGES:

--LINE 0029 INCLUDE VERBIAGE CHANGES TO INCLUDE CUSTODY BY POLICE, JAIL OR PENAL INSTITUTION
--CURRENT POLICY OF PRISON SYSTEM
--ALL SUCH DEATHS MUST BE AUTOPSIED
--OPINION OF INDEPENDENT, OUTSIDE PATHOLOGIST
--ELIMINATES CHARGES OF COVER UP BY STATE CONTROLLED PHYSICIAN
--DOCUMENTS CAUSE OF DEATH, MAY ELIMINATE SPURIOUS CHARGES, LITIGATION
--MEANS OF MONITORING QUALITY OF MEDICAL CARE
--JURISDICTION OF DEATHS IN STATE INSTITUTIONS NOT SPELLED OUT IN STATUTES
--DOES LOCAL CORONER HAVE JURISDICTION TO ORDER AUTOPSY ON DEATH OF ALL INMATES OF STATE PENAL INSTITUTIONS?

KSA 1975 SUPP. 19-1030--INQUEST

--CHANGE SHALL TO MAY REGARDING CORONER HOLDING INQUEST
--SHALL = MANDATORY; MAY = OPTIONAL
--OUTMODED, UNNECESSARY EXERCISE IN FUTILITY
--NO LONGER NEEDED WITH PRESENT SCIENTIFIC INVESTIGATION OF DEATH
--INFREQUENTLY HELD, HENCE, VIOLATION OF THE STATUTES

KSA 1975 SUPP 19-1033--RETENTION OF SPECIMENS

--CHANGE "AS LONG AS NECESSARY" TO SPECIFIC TIME--3 YEARS.
--HOW LONG IS NECESSARY?
--MUST CONSIDER COST OF STORAGE

HOUSE BILL NO. 2777

W. Howard Whiteside, M.D. - Pediatrician and Director of Neonatology - SJMC

Representing: The Kansas Perinatal Committee

Aim: Improvement in the detection of SIDS victims, discovery of the exact etiology and development of simple and effective screening techniques.

Sudden Infant Death Syndrome (SIDS) originally described an infant for whom a cause of death could not be determined either by history or autopsy. Physicians feel uncomfortable with a condition that is of unknown etiology, and is also the most common cause of death in infants between 1 week and 1 year of life. For the parents of a SIDS victim, the sudden loss of their own flesh and blood, the baby who was responding to their voices, smiling, laughing and totally innocent, is almost beyond belief. This is a condition that effects other babies, not their's. They feel that they must have done something wrong. If only they had checked on the baby a few minutes earlier. Maybe if they had seen their doctor for the slight stuffy nose. Every possible self incriminating thought enters their head - they feel totally responsible, since this young baby was totally dependent on them. The final insult, is to be told that no cause of death was identified, and no abnormal pathology was found at autopsy. These parents will go through a severe grief reaction, and often feel very guilty and may become very angry, but the anger often cannot be directed at anyone specific, so it is internalized or directed at the closest relative, commonly the spouse. The stress itself may result in marital break up and severe depression, amongst other conditions.

Appropriate attention to the many concerns of these parents, is of utmost importance. They will commonly desire another child, but fear that this child will also suffer from the same demise - the "black death" will come again in the middle of the night and take their child. This is a common experience for many parents of SIDS victims, but things are changing. The mysteries of this dreaded condition are being unraveled in various major centers around the country and world. During the past few years, various pathological markers have been identified, thus enabling physicians to understand the various mechanisms that may be responsible for SIDS. Pulmonary edema (lung fluid) is present in more than 95% and intrathoracic petechial hemorrhages are present in more than 75%. Evidence of minor infection occurs in 75%. Respiratory syncytial virus being commonly implicated. Some studies have shown that the surfactant isolated from lungs of SIDS victims is defective and therefore may not support alveolar (air-sac) expansion at low lung volumes. A pathologist by the name of Naeye in 1980 concluded from a series of autopsies on SIDS victims that chronic intermittent hypoxia may have been

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present prior to death. A more recent study has reported higher fetal hemoglobin in SIDS which, would support the "chronic hypoxia" hypotheses. A decrease in the number of myelinated fibres in the vagus nerve in SIDS victims may have relevance to lung receptor function. Other findings include a decrease in the number of myelinated fibres in the vagus nerve, which may have relevance to lung receptor function, and possible changes in the carotid bodies and/or the levels of dopamine and noradrenaline in these bodies, that could impair ventilatory response to hypoxia

To detect and interperate correctly these many features, requires a pathologist with experience and ideally a special interest in SIDS. The abnormal autopsy findings will help parents of SIDS victims to understand that their child's death was not a result of their neglect, but unfortunately because of circumstances beyond their control. In addition, the autopsy will detect causes other than SIDS, which may require very different counselling and implications for future children, and may detect child abuse with its own scenario.

Our state statistics reveal that we are already performing autopsies on 75% of suspected cases. This number should be nothing less than 100%, and it is only by mandating this, that things will change. We need to make a positive diagnosis in infantile death and therefore be able to council parents appropriately, giving them guidance as to the risks of future children suffering from the same demise.

In conclusion, SIDS is the most common cause of death between 1 week and 1 year of life, and appears to be often a biphasic phenomenon consisting of a predisposing factor plus or minus conditions such as an upper respiratory infection. The diagnosis can only be made with an autopsy, and this autopsy must be performed by a pathologist with experience in this field.

This bill, if passed, will achieve the desired 100% autopsy rate in infants. With the aid of an experienced pathologist the results will not only provide a diagnosis, but will aid in our understanding of the disorder, its early detection, and hopefully a decrease in the incidence.

**CARRIE SHEEHAN**
WESTERN REGIONAL DIRECTOR
NATIONAL SIDS FOUNDATION
915 16TH EAST, SEATTLE, WA 98112
(206) 329-7922

February 25, 1988

Honorable Members of the Kansas State Legislature:

I am happy to have this opportunity to come from Seattle, Washington to express from my perspective the need for autopsy legislation for infants who die suddenly and unexpectedly. As the Western Regional Director for the National Sudden Infant Death Syndrome Foundation I manage 25 chapters in the 19 Western United States.

In the 33 years since my daughter died I have seen as many theories come and go. Still no cause is known why babies die of SIDS. The only thing we can offer parents is a piece of paper, the autopsy report which shows that by exclusion of known diseases the death can be labeled SIDS. As you might know SIDS or "overlaying an infant" has been with us since Biblical times. Such is the story of Solomon deciding the fate of the surviving infant. Medieval times relay horror stories of mothers put to death for what was then thought to be smothering. It was parental concern in the early 60's that initiated the SIDS movement. Washington State's legislature was the first to authorize funding for autopsies and the studies of statistics that followed. It was the forerunner of the Federal SIDS Act of 1974.

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Prior to 1975, the Government's involvement in SIDS was limited primarily to research. The SIDS Act of 1974, required the United States Department of Health and Human Services to develop public information and professional education materials relating to SIDS and to disseminate them to persons providing health care, public safety officials and the general public. These direct grants to states and programs under the SIDS Act ended in FY 1982. The legislation that followed included but did not mandate state MCH Block Grant funding of SIDS projects or activities. Given that freedom to alter their investments among MCH programs under the Block Grant, many states did not make substantial changes in their budgets and priorities. Autopsies were not a priority.

At this time I believe we have 29 states with some type of laws: 18, with some form of specific SIDS legislation. Last month the Oklahoma State Legislature held preliminary hearings at which strong support was voiced by the medical examiners office, professionals and parents. At our 25th Year Anniversary Meeting held in Washington ,D.C. last fall a mandate was given by parents for federal legislation. Such action, of course, will not happen overnight.

I would guess the questions you might ask are: Is it really necessary? Definitely, it is, since it is an entity of exclusion,

it is the only peace of mind that a family can have. Suicide and divorce rates are higher than average among SIDS victims. The autopsy report with a sensitive and intelligent explanation is the only current answer that can be provided for this mysterious death.

Who is the autopsy important for? Obviously the families who are the real victims. However, it is reported that for each SIDS death 20 community members are affected...the doctor, who thinks he or she may have missed a diagnosis; the emergency room personnel who feel they were inadequate in the resuscitation efforts; siblings who may, through their guilt, blame themselves; daycare workers and other caregivers. Recently a daycare worker described it as having "rented out her psyche" . The parents need to know the outcome for their future family planning, and more recently the gray line between child abuse and SIDS is blurred. Oftentimes law enforcement under the strain of child abuse cases are overzealous in their pursuit of a cause for the effect that leaves SIDS parents in double jeopardy. Is it cost effective? From my experience, I would say that state monies are far better spent on autopsies than wrong arrests, criminal trials and the mental health toll of no or a wrong interpretation of a sudden infant death. Finally, the catch 22, ---research monies are not available without statistics and without autopsies there can be no statistics.

At the turn of this century in America it was not uncommon in many families to experience infant death. Today, we do not expect it. And yet in our countryin 1988 the sudden death of an infant becomes a fact, a reality for a family, once every hour.

The poet Robert Frost, who suffered the death of his infant, wrote in the poem Home Burial ,

" The nearest friends can go
With anyone to death, comes so far short
They might as well not try at all."

Such is not true now for those victims of SIDS who have been given scientific facts, the autopsy report, compassionate support of other parents and hope derived from current research. We have come a long way since my daughter, Molly, died . With countless others we will block the road for any who might wish to return to the past.

Thank You.

THE KANSAS SOCIETY OF PATHOLOGISTS

TESTIMONY

re: House Bill 2777
Feb 25, 1988

Mr Chairman, members of the committee, thank you for the opportunity to speak to House Bill 2777.

My name is David De Jong, and I am from Wichita. I speak to you as a pathologist who is the second or third most active in the number of forensic autopsies in the state of Kansas, as the secretary of the Kansas Society of Pathologists who has polled a number of the members who are doing such autopsies, and as a physician who for a number of years has been particularly interested in the tragedies of Sudden Infant Death Syndrome and child abuse, the two problems that will be affected the most by this bill.

The pathologists of the state are generally supportive of this bill. None has spoken against it to me, although there has not been sufficient time to hear from everybody. There are some recommendations and some concerns that have been expressed. They follow:

1- There is no point or reason for this change in the present version of HB 2777. We feel there should be a committee of pathologists and pediatricians whose responsibility will be to monitor and evaluate the results of this program on a regular basis, perhaps quarterly. It should be responsible to see that only qualified individuals perform the examinations, that those examinations are complete according to an appropriate protocol, that they are carefully done and that the results are of value to the state.

Attm. #10
2-25-88
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2- Since HB 2777 represents a limitation of coroner discretion as well as a significant cost, we recommend that a sunset clause be placed on it, perhaps six years. This will allow an accumulation of 5 years data and enough time to evaluate the results and make recommendations on whether to continue it or to let it lapse.

3- Since most of the coroners in Kansas are not pathologists, but rather are surgeons, family practioners etc., some of whom have done autopsies, the bill should be clarified so that it does not direct the coroners themselves to perform the post mortem examinations, but to ensure that they are performed by a qualified person.

4- There are some simple wording changes that will prevent confusion:

a. Since stillborn infants are not part of this study, we recommend the addition of the word "liveborn" in line 37 so that it reads: "When a liveborn person under .....".

b. Lines 56 to 58 are inappropriate and medically incorrect, since legislative fiat does not make a correct diagnosis nor should it lead to inaccurate ones. Instead, if the usual penalties inherent in not following the law need to be reinforced, it should be done here.

5- We have heard a funding estimate of $500 per case. A more realistic estimate across the state is $1000 to cover professional fees, ancillary costs (laboratory, x-ray, special studies) and administrative costs such as transportation, facility use, etc.

The following are a few additional comments:

There is a particular laboratory test that should be done in all such cases, since it appears to distinguish 80 to 90 % of cases of SIDS. It appears that one way to ensure such an occurrence is by the use of a protocol as mentioned in item 1 above. Secondly, a single laboratory should perform the test to standardize it across the state. All of this can be ensured by an oversight committee as mentioned above.

I believe that these cases should be studied by a pathologist experienced and interested in forensic and medicolegal problems for several reasons. There are not many young children dying unexpectedly in the state, fortunately, but they are distributed across the state and that means that only a few places see more than 1 or 2 cases a year. Since it is rather unusual for medical illnesses not to manifest problems ahead of death, the most common differential diagnosis is unsuspected child abuse. The findings that lead to that diagnosis are often subtle and not part of the usual medical autopsy, nor are those autopsies conducted with a view to obtaining proper photographic or other evidence. Obviously such cases also require a willingness to go to court and an ability to give clear testimony there.

Finally, the Kansas Coroners Association has expressed to me its disappointment to have heard of the bill so late, and that it would appreciate more time to review it.

KANSAS CHAPTER/NATIONAL SUDDEN INFANT DEATH SYNDROME FOUNDATION
RR 2 NORTON, KS 67654 (913)6934375

February 25, 1988

Like many things in todays world, when it comes to Sudden Infant Death Syndrome and the impact this entity has on the family and the community it doesn't just effect those intimately involved, it affects society as a whole.

This can happen when others around the family question their worth as loving and protective parents. As parents we are taught to protect our young from all dangers but how can we protect a content and sleeping infant from something we can't see, or hear and has no warning symptoms? The one and only symptom is death.

The parents suffer by their own "If's" enough without the worry of being suspected of child abuse or neglect--by well meaning family, friends, or acquaintances. Without the benefit of an autopsy, they have nothing with which to console themselves or others. No final findings to base the decision of having a subsequent child in the years ahead, should they make that choice.

A mandatory autopsy law for Kansas could mean that as a nation, we could get closer to discovering the cause or causes of SUDDEN INFANT DEATH SYNDROME and eventually put an end to this silent killer. But most of allit would stop the destruction it leaves in it's path when it strikes a sleeping infant at random.

attm. #12
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PH&W

Verla Britton, President

*. . in the belief that every child should live*

TESTIMONY CONCERNING
MANDATORY AUTOPSY LAW
FEBRUARY 25, 1988

As are several of the others here this afternoon, I am the parent of a SIDS victim. Her name is Annie. She would have been seven years old next month. However, I am also here as a former RN who, ironically, specialized in the care of the sick and/or premature infant. I have lost my daughter and some of my patients to Sudden Infant Death Syndrome. And it is my belief that the significance of the legislation that we are proposing is even more understandable when we keep both of these perspectives in mind.

This generation has grown accustomed to raising its children to adulthood. And, there is good reason for that attitude. I have been privileged to witness for myself the explosion of knowledge and technology that has improved the odds for the premature or sick infant that is born in this day and age. Babies that yesterday wouldn't have had much of a chance for survival, are now not only doing so, but most are looking forward to a creative and sustantive life. I was, and still am proud of the work that was being done in that nursery. And, one of the happiest parts of my job was to send home an infant that had "beaten the odds". And, we were careful to tell the parents what to look for in the care of their child. We would say things like, "Keep your baby out of crowds for the first few weeks. Be sure to feed your baby every three hours until they have achieved a certain weight gain. Elevate the head of their crib if they develop a runny nose or other cold symtoms and

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then call your doctor." But we had nothing to tell them to prevent their child from dying of SIDS. And some of them did. When that happened, I would always feel a little bit of guilt, wondering if there had been something that I could have said or done that would have made a difference in the baby's outcome. But, more than guilt, I would feel an overwhelming sense of frustration. In particular, I remember two patients that we had worked on for over two months. Over two months, only to have some syndrome whose pathology we can neither trace nor predict, wipe out all of that work in seconds.

One afternoon, after giving a lecture on SIDS, I spoke to a young family practice resident. Sadly, the very first baby that he delivered died of SIDS. He voiced his frustration this way, "I would have done everything that it was in my power to do, if only I had known that I was supposed to be doing something. I examined that child several times. I would have sworn that she was healthy." His words speak eloquently to the frustration and bewilderment that the medical community feels about this syndrome. Those words echo my own frustration and guilt over my daughter's death, as well. The truth of the matter is that, though there is much that pediatric medicine can do for the sick or premature infant born today, there is a select number of normal, healthy-looking infants for which we have no answers.

What we know about SIDS sounds more like the MO for a cat-burglar than it does for a medical syndrome. We know that SIDS is quiet, over-taking its victims while they are asleep in their cribs. We know that it strikes randomly, selecting its victims from every race and socio-

economic circumstance. We know that it happens most frequently where parents feel safest about their children, the home. And, finally, we know that we cannot predict when or where it will strike next.

We do not now have many answers for me, or other SIDS parents like me as to why our children died. But, we are learning. And, a good deal of what we are learning is gleaned from autopsies. It is not an easy way to learn. Autopsy is not the fate that I would have picked for my Annie. But, when the one and only symtom is death, then autopsy is the only way that SIDS can be studied under the actual circumstances.

Unfortunately, with the law in existance, autopsy can be waived when the coroner suspects SIDS. Believe me, I understand the motivation to waive autopsy for suspected SIDS victims was one of compassion and sensitivity for the parents involved. And, it is not just from the medical standpoint that I favor adopting this mandatory autopsy law. It is also for the parents that I am concerned. I can say with all candor that I am glad that an autopsy was performed on our Annie. For, in the dark hours of my grief, I could, by virtue of the information on Annie's autopsy, reassure myself that their was no hidden abnormality that took my daughter's life. There is nothing that I, as a nurse and mother, could have done to save her. And, when our next child was on the way, I could remind myself that there had been nothing genetically wrong with Annie that could be passed on to the new baby.

This legislation is important, too, because we need to insure that SIDS is called SIDS. It is not virulent pneumonia or sudden cardiac failure. Nor is it possible suffocation or regurgitation. The only thing

that those terms do is serve to create further grief on the part of the parents because they insinuate that there was something about our baby that could have been observed and treated. We are already overburdened with guilt over losing what seemed to be a healthy baby. It would be an act of kindness for the state of Kansas to see to it that the results of an autopsy don't add to the guilt. SIDS is SIDS. It is neither predictable nor preventable. The fact that there are times when doctors choose to call it something else on an autopsy is, I believe, the doctor's frustration in not finding anything else there to diagnose. If we as a generation find it difficult to accept the fact that seemingly normal infants die for no apparent reason, then we should be able to understand that doctors are no different. They may intellectually come to terms with the facts, but they still have a basic impulse, like the rest of us, to assess responsibility to something. Hence, the need for using terms other than SIDS. And, when other terms are used, then valuable information is lost. And that makes studying data that much more slow and difficult.

At this time, the counties now pay for autopsies. For larger counties this is not as much a travesty as it is for the smaller ones where the funds are not very large. As the law now stands, it is possible for the coroner to assume that the cause of death is SIDS and waive the autopsy. In doing so, he does save the county the cost of a post-mortem, but the lack of an autopsy creates its own set of problems to which I have already spoken. In the end, an autopsy is an act of compassion for the parents of SIDS victims and means to answers on behalf of all future babies and their parents.

Annie's death left a grieving mother and father, as well as grandparents, aunts, uncles, friends, neighbors, and an older sister. If she had lived, Annie would have had two younger brothers. And all of us desparately want to know why she died. This same scenario will be played out approximately 75 times across the state this year. Add that to the number of children who have died in years prior, and one can begin to understand the significance of this piece of legislation. It is my prayer, indeed, my firm belief, that by passing this mandatory autopsy law, we will speed the day when the SIDS parents in this room will know how their baby died and how we can keep other babies from dying because of this untraceable and unprdictable syndrome. I think that I speak for every SIDS parent in this room when I say that we already know what it is like to be SIDS parents. We don't want to know what it is like to be SIDS grandparents!

February 25, 1988

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Last year, on Feb. 4 I gave birth to my second child. Christopher was a beautiful healthy 7 pound 10 ounce full term baby. On March 22 while he was taking his afternoon nap he stopped breathing. At Stormont-Vail Emergency Room the doctors revived his heart after two hours of CPR. On March 23 Chris turned 11 weeks old. On March 24 he was officially pronounced dead. He had all the classic symptoms of Sudden Infant Death Syndrome (SIDS). His death certificate says the primary cause of death was aborted SIDS, the secondary cause was cardiac arrest, but that might not be true.

Before Chris was really dead the Doctor said that an autopsy might need to be done. My husbands and my reaction was not very positive, we did not want "that" done to our son. But we were only thinking of the situation at that moment. The subject of autopsies was never brought up again and we did not have one performed. Since then, there have been times that my husband and me wondered if there was something else that killed Chris but now we will never know. As of yesterday, it has been 10 months since Chris died and we are trying to have another baby and we wish we knew if Chris really died of SIDS or if it was something else. If we had an autopsy performed we would have a better idea if our next child is at risk of the same thing.

I'm like most other people, I don't like the thought of autopsies. But now, I realize the value of autopsies as a part of greiving, family planning and the research value that they have. It is because of those three reasons that I support the addition of this section to the current autopsy law. I also support the changes that the Kansas Department of Health is proposing.

SUDDEN INFANT DEATH

I want to thank you all for giving us this chance to speak on the behalf of the sudden infant death syndrome foundation concerning mandatory autopsy law for the state of kansas.

My husband and I lost our child Jason on the 25th of January 1986. At that time we resided in Rose Hill, Kansas, Butler County.

Jason was found by my husband at 8:00 am. He immediatly called 911. Emergency Medical Techanicians arrived at our house immediately and performed all necessary measures to save our son . They decided to transport Jason to Wesley Hospital which is located in Wichita, Kansas, Sedgwick County.

The ambulance which was transporting Jason from Rose Hill was met outside of Butler county by a pediatric ambulance, out of Wesly hospital. Jason was transferred to this pediatric care unit and rushed to Wesly.

At 9:30 am, Jason was pronounced dead. At this time hospital personel informed me that an autopsy would be performed. At 12:30 pm as we were leaving the hospital a nurse ran after us and told us that the doctor had changed his mind and decided not to do an autopsy, and if we wanted one it was our choice.

Attm #15
2-25-87
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Why was it our choice on wheather to go ahead and let them perform an autopsy. Because Butler county was responsible for payment, Jason was prononced dead in Sedgwick county, but died in Butler

county. The Sedgwick county coroner said Sedgwick county was not responsible for payment so before an autopsy was performed in Sedwick county, Butler county coroner had to okay it.

Was it okayed? Butler county told us they okayed the autopsy, Sedgwick county denies this claim. If there was a mandatory autopsy law, this type of mis-understandings would not take place. So who's court is the ball in now, two hysterical parents, being my husband and I. From our own experience this is not a time for anyone to be making a critical decision. You have just had your whole life shatterd. In the end my husband and I were really confused and choose not to have an autopsy performed.

How do we feel now? Regretful.
Why? I kow deep down inside I will never know myself what took my sons life. If I want to belive the doctors experience in Sudden Infant Death I would belive he doesn't really know himself. If I was to ask the doctor to swear before me & God that he knew for a fact that SIDS is what Jason died of, he could not answer yes. But, He could of answered yes if an autopsy had been performed. The doctor would have known, and we as parents would have known.

Lets look at the cause of Jasons death being, not that of SIDS. Any futher childern I decide to bear could be at a greater risk of an unkown disease. My living children I now have could be at a risk of an unknown disease to me.

Sure, Jason was a healthy 13lb baby boy when he died, and he had all the charateristics of a SIDS baby, or as they say the tell tail signs. No one will absolutely know for sure without an autopsy.

I really believe that in the long run parents, doctors, family will feel more at ease with an autopsy, taking uncertainty and guilt away from all. Let me elaborate on the guilt; parents, grandparents and medical personel could and do feel,the majority of deaths have known causes. Reasons for the death. A SIDS baby has no known cause. Which leaves the parents to blame themselves.

I remember wondering and questioning myself on what I did wrong to cause Jason to die? What did I eat? What could I've done to prevent this death? What did I do to cause this harm to my baby. I had no one or no disease to blame for my sons death. So who does one turn to, yourself. I had two previous children to Jason. In this day an age I was considered a pro by all my collegues, on child rearing. Sure I was told Jason died of SIDS and there is a part of me that believes that is what he died of. But know-one will really ever know. And, believe me it is a very empty and sometimes scary feeling I will carry with me for the rest of my life.

I am very thankful to the SIDS organization for the support they have given me in the last two years. And I have learned to except Jasons death. But looking back at the last two years I can think of many times being asked if Jason had an autopsy and being ashamed to answer no, wishing I could answer yes. Beleive me no young couple wants to think of their baby being autopsyed after they loose them so suddenly. But I cannot think of one couple whose ever regretted having to have an autosy as much as we have regretted not having one.

Thank you.

MANDATORY AUTOPSY

Testimony

by

Debra Wells

Attm. #16
2-25-88
PH&W

Friday, May 16, 1980 began like any other day. The baby was up at 5:30 a. m. for his bottle and a diaper change. After our morning quiet time, he sat in his swing while I readied myself for work. (I had returned to my teaching position just the week before to close out the school year so I could devote myself to being a full-time wife and the mother of a newborn son and an 18 month old daughter.) Just a few more days, I thought to myself that morning. Before I left the house at 7:00 a. m., I remember kissing my son and sharing my thoughts aloud. Just a few more days . . . .

Those were the last words my son heard from his mother. At 2:30 that afternoon, I received a call at school. My son had been rushed to the hospital. The 20 minute drive to the hospital was the longest of my life. What possibly could have happened to my beautiful baby boy?

Upon arrival at the hospital, I was escorted to a private room. Within a matter of moments, the circumstances and tragic consequences of an afternoon nap were made all too clear. Our baby had died suddenly and unexpectedly.

After telling us of our son's death, our family physician asked us if we wanted an autopsy. Our son had suffered enough; nothing would bring him back. We declined the autopsy. (It is important that you understand our ignorance of autopsies and our gross misconception of what would be done to our child if an autopsy were performed. No one explained either the need for or the manner in which an autopsy is done.)

We were given some private moments with our son in one of the hospital's emergency examining rooms. After our final good-bye, we returned to the private room we had been given only to be told that our son's death was being classified as a coroner's case. An autopsy was mandatory in all cases such as this. The decision for autopsy was out of our hands. We received no explanation and were given no opportunity to ask any questions.

I now know the necessity of an autopsy. And had I known then what I know now, I would have agreed to the autopsy. I also believe if someone had told us why it was an important that an autopsy be performed, we would have understood. But to throw the words "coroner's case" at us without any explanation caused us a great deal of agony. What had happened? What did they suspect?

In mandating autopsy, it will be very important that parents be told the need for an autopsy. They must be reassured of the compassion and delicacy with which it is performed. In the great majority of cases of sudden and unexpected death, the parents (or care-givers) must be above suspicion. Autopsy will identify without doubt a cause of death. If, upon autopsy, their is reason for suspicion, the case can be handled accordingly.

I fully support mandatory autopsy legislation for all cases of sudden, unexpected death in infants. The only way to be absolutely certain of the cause of death is through autopsy. The results can assure parents that their child was not a victim of neglect or abuse; that his death was not a result of something they, or a care-giver, did or did not do. It can rule out the possibility of genetic defects that might be passed on to subsequent children. A diagnosis from autopsy gives parents a cause of death, a reason to explain and attempt to understand the tragedy.

A second issue of equal importance is that autopsy results be made available to the parents within a timely manner. Everyone the parents encounter wants to know what happened to the baby. Parents need educated answers, not guesses. Until they have the autopsy results, neither they, nor anyone else, can be certain why the baby died.

It took me over six weeks to find out why my baby died. I made several phone calls in the days and weeks following his death and was either referred to another number or told I would have to wait until the autopsy results became a matter of public record. For six weeks I hung on to the words "sudden infant death syndrome". Our physician had mentioned SIDS as a possible cause of death in the emergency room. And even though we had a possible cause, somehow, knowing that an autopsy had been performed, I was desperate to see in writing or hear from a qualified source, why my baby died. Without persistence, I would never have had the answers I needed. After several calls to the County Clerk's office over a matter of several weeks, I finally learned the autopsy results were on file. I drove to the Clerk's office, identified myself as the mother of the victim and paid 25¢ per page for a copy of the autopsy results. My baby had died in May and it was July before I knew why.

Unfortunately, despite the frustration of my situation, I am one of the lucky ones. There are many parents in the State of Kansas who never know why their baby died. They either did not have an autopsy performed and someone is "guessing" why their baby died or they did not have the stamina and persistence in a weak emotional state to fight the red tape it took for me to get the answers I so desperately needed.

It is very important that upon completion of the autopsy, a qualified medical professional convey the results to the parents. He will be able to answer any questions they may have surrounding the death and he can reassure them that the cause of death is definitive. Parents have a need to know. I belive they should also have the right to know why their babies are dying. By

mandating autopsy legislation and requiring that the information be given to the parents as it becomes available, the State of Kansas will join the many other states nationwide who have recognized the need for this important piece of legislation.

Thank you for taking this proposal into consideration.

Debra Wells

Debra Wells

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Testimony Presented to

House Public Health and Welfare Committee

by

The Kansas Department of Health and Environment

House Bill 2777

Perhaps the most tragic of all infant deaths are those attributed to sudden infant death syndrome (SIDS) or when an infant is found dead due to no apparent cause. Grief in this situation is an intense, lonely, and personal experience. When a child dies suddenly, not only does the death destroy dreams and hopes, but forces the family to face an event for which they were unprepared.

SIDS is the leading cause of death in the United States of infants between 1 and 12 months of age. Currently, SIDS accounts for approximately 5500 deaths each year in the United States. Most of these babies (approximately 92%) die between the ages of one month and 6 months. For the past five years Kansas has averaged 56 SIDS deaths per year. Of these, 25% had no autopsy performed.

Providing access to an autopsy will help determine the cause of death and rule out, for example, brain hemorrhage, viral causes, or reaction to an immunization. These families need to have no doubt left in their mind regarding the cause of death.

An autopsy can conclusively determine the cause of death where SIDS is suspected. The Kansas Department of Health and Environment (KDHE) was charged in 1915 to study the causes of infant mortality. Accurate reporting of the cause of death, based on an autopsy, will assist us in evaluating the multiple causes of infant deaths. The health care professional has the obligation to investigate the cause of death, and then, in the typical instance, of assuring the parents and family that nothing they did or did not do was in any way responsible for their infant's death. Providing the autopsy results, with appropriate explanations to the family, and referring them for support and counselling should facilitate the resolution of the family's guilt.



Attm #11
2-25-88
PNEW

We support House Bill No. 2777, which would require mandatory autopsies for deaths suspected to be caused by SIDS, or if the death is of an unknown cause. We do, however, recommend that New Section 2 of this bill be amended to include: 1) autopsies in these cases be done by a competent pathologist; 2) the phrase "under two years of age", be changed to "in the first year of life"; 3) a copy of the autopsy report for these deaths be forwarded to the Kansas Department of Health and Environment; and, 4) the Kansas Department of Health and Environment be the payor of last resort for these autopsies.

Presented by:

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Coordinator, Health Services for Mothers and Children

February 25, 1988