

MINUTES OF THE SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

The meeting was called to order by Chairman Jim Barnett at 1:30 p.m. on January 26, 2010, in Room 546-S of the Capitol.

All members were present.

Committee staff present:

Nobuko Folmsbee, Office of the Revisor of Statutes
Renaë Jefferies, Office of the Revisor of Statutes
Iraida Orr, Kansas Legislative Research Department
Terri Weber, Kansas Legislative Research Department
Jan Lunn, Committee Assistant

Conferees appearing before the Committee:

Ron Hein, Counsel for Midwest Transplant Network
Rob Linderer, Chief Executive Officer, Midwest Transplant Network

Others attending:

See attached list.

Chairperson Barnett welcomed students from the University of Kansas Nurse Anesthesia Program: Christopher Morrissey, Donna Nyght, Paul Hertel, Todd Nason, Tara Brunin, Andrea Yoder, Andrew Sledge, Heather Fenton, and Dustin Bozwell.

Susan Kang, Kansas Department of Health and Environment (KDHE), requested introduction of three bills:

- 1.) A bill amending licensure of audiologists and requiring those seeking licensure to hold at least a doctorate degree, or its equivalent, in audiology.
- 2.) A bill regulating food and beverages in school vending machines and school stores that would require those items comply with KDHE wellness policy guidelines.
- 3.) A bill requiring chain restaurants provide nutritional and calorie information on menu boards or menus.

Upon a motion by Senator Kelsey and a second by Senator Brungardt to move introduction of the three bills discussed by Ms. Kang, the motion passed.

Mr. Mack Smith, Executive Secretary, Kansas Board of Mortuary Arts, requested introduction of a bill related to licensure and fees of crematory operators.

Upon a motion by Senator Schmidt and a second by Senator Brungardt to move introduction, the motion passed.

Mr. Bud Burke, representing the Kansas Physical Therapists Association, requested introduction of a bill related to physical therapists and their evaluation and treatment of patients.

Upon a motion by Senator Brungardt and a second by Senator Kelsey to move introduction, the motion passed

Renaë Jefferies, office of the Revisor of Statutes, briefed members on **SB 391 - Anatomical gift; first person donor registry**. She explained that two statutes in the Revised Uniform Anatomical Gift Act would be amended. It would clarify that an individual who agrees to have his or her name in the registry has given full legal consent to the donation of his or her organs or tissues upon death. The bill also amends statute to permit a donor to amend or revoke an anatomical gift by directly accessing the registry website or notifying the Kansas federally designated organ procurement organization to request the amendment or revocation. Ms. Jefferies requested a technical amendment to cite the proper statute of K.S.A. 65-3239 and to enumerate these statutes appropriately.

Rob Linderer, CEO, of the Midwest Transplant Network, testified in support of **SB 391**. Mr. Linderer described his organization and the Missouri counties it serves in addition to serving the State of Kansas. He indicated the amendments would strengthen and clarify the Kansas

CONTINUATION SHEET

Minutes of the Senate Public Health and Welfare Committee at 1:30 p.m. on January 26, 2010, in Room 546-S of the Capitol.

Uniform Anatomical Gift Act regarding decisions to donate anatomical gifts prior to death, and that the first person registry would provide an effective mechanism for donors to have their desires for organ donation registered and recognized (Attachment 1).

Senator Kelsey asked if this bill would alter the requirement to include "organ donor" on an individual's drivers license. Mr. Linderer indicated that with implementation of the first person registry, the Midwest Transplant Network's web-based portal would serve as entry point with the Department of Motor Vehicles (DMV) serving as an additional port of entry through software downloads to the Kansas Registry.

Senator Kelly inquired about security of the web-based application and whether the Kansas Registry crosses state lines. Mr. Linderer reported the same technological safeguards employed for on-line banking, for example, were built into the Kansas Registry; however, nothing is absolute. Insofar as crossing state lines, Mr. Linderer affirmed that procurement organizations located in the area where the donor dies would facilitate an interstate search.

Senator Colyer requested explanation concerning revocation and the language that "withdrawal of the individual's consent does not constitute a refusal to make an anatomical gift." Mr. Linderer clarified that if revocation occurs, the registry reverts to the current practice which allows secondary consent from the individual's family for donation to occur. In the case where a donor has revoked his original decision, the only method to ensure that no donation occurs is to have a legal document prepared indicating that no anatomical donation through secondary consent is allowed.

Senator Barnett questioned whether a first-person consent via paper can be documented with subsequent entry into the Midwest Transplant Network Kansas Registry. The question relates to individuals who may be unable to access electronic resources. Mr. Linderer confirmed that paper copies can be requested and delayed entry by clerical staff into the Registry will be performed.

Senator Huntington inquired whether juveniles can be organ donors. Mr. Linderer responded that for juveniles age 18 and older, consent can be given by the individual; parents are responsible for organ donation decisions for minors under age 18.

Ron Hein, representing the Midwest Transplant Network and the Missouri-Kansas National Kidney Foundation, spoke in support of **SB 391**. Mr. Hein shared his personal experience as a recipient of organs resulting from Type 1 Diabetes Mellitus (Attachment 2). He discussed the importance of organ donation in the preservation of life.

Senator Haley inquired about the process for selecting recipients within a transplant network. Mr. Linderer responded that the United Network for Organ Sharing (UNOS) is the national organization accountable to ensure that all transplant networks have policies, procedures and protocols in place for organ procurement and distribution. An individual with an urgent transplant need must meet stringent, established criteria.

Senator Kelly moved to amend **SB 391** as discussed during Ms. Jefferies bill briefing. Senator Schmidt seconded the motion which passed unanimously.

Senator Kelsey moved to pass out favorably **SB 391** as amended. Upon a second by Senator Colyer, the motion passed.

Senator Barnett adjourned the meeting at 2:29 p.m.

**PUBLIC HEALTH AND WELFARE
GUEST LIST
January 26, 2010**

NAME	AFFILIATION
Bud Burke	KS Physical Therapy Assn.
Sarah Towell	KNA
Tracy Hill	Washburn University - School of Nursing
Pam Scott	Ks Funeral Directors Assn
Kari Presley	Kearney & Associates Inc.
Mack Smith, ^{EXEC} _{SEC}	KS STBA of Mortuary Arts
Jackson Lindsey	Heinlaw
Hannah Sanders	Kansas Health Policy Authority
John Kieffer	Ks. Chiropractic Assn.
TODD NASUN	Univ of Kansas SRNA
CHRISTOPHER MORRISON	University of Kansas SRNA
Andrea Yoder	University of Kansas SRNA
Heather Fenton	UNIVERSITY OF KANSAS SRNA
Alonzo Nye	University of Kansas Nurse Anesthesia Education.
Aime Spiess	American Cancer Society
Tara Bruner	University of Kansas Nurse Anesthesia Edu.
ANDREW SLEDGE	UNIV. OF KANSAS SRNA
Paul Hertel	Kansas Association of Nurse Anesthetists
Michelle Buller	Capital Strategies

**TESTIMONY OF THE MIDWEST TRANSPLANT NETWORK,
BY ROB LINDERER, CHIEF EXECUTIVE OFFICER
BEFORE THE SENATE PUBLIC HEALTH AND WELFARE COMMITTEE**

**TUESDAY, JANUARY 26, 2010
IN SUPPORT OF SB 391
FIRST PERSON CONSENT DONOR REGISTRY**

Mr. Chairman and members of the Committee,

I am Rob Linderer, Chief Executive Officer of the Midwest Transplant Network based in Westwood, Kansas. My organization is a non-profit, federally certified organ procurement organization (OPO) designated to serve the state of Kansas and 63 counties in western Missouri. Under Kansas law, Midwest Transplant Network is also identified as the organization responsible for operating the existing state donor registry.

My testimony is in support of Senate Bill 391, which would strengthen and clarify the provisions of the Kansas Uniform Anatomical Gift Act that allow an individual to make a decision to donate anatomical gifts prior to their death. Currently, that can be done through the DMV by agreeing to be a donor and having a "symbol" placed on the license, signing the back of the license, a donor card, will or other legal document. In each of these circumstances, it is necessary that these documents be readily available at the time of death, which rarely occurs. The existing registry provides the next of kin with unvalidated evidence of "intent" to be a donor, but without a signed will, document or drivers license available, the donor's wish can be overturned by others.

SB 391 would clarify that by entering your name in the Kansas State Donor Registry you are giving first person "consent" for donation consistent with the provisions of the Uniform Anatomical Gift Act. An individual will continue to register through the DMV when obtaining or renewing their driver license, or by directly accessing the Kansas Donor Registry website. To implement the requirements of SB 391, a web accessible, donor registry computer software application will be deployed by the Midwest Transplant Network. This registry application has been developed and successfully deployed by the

state of Missouri with the support of a federal grant. This application is available to Midwest Transplant Network and will be deployed and operated as the Kansas Donor Registry. The application will give Kansans the ability to authorize an anatomical gift that cannot be revoked by others after their death. It will allow the individual to indicate any limitations to the gift and also provide a means to revoke a gift should they decide to do so.

Kansas was the first state to pass the Uniform Anatomical Gift Act in 1968 and has continued to update and revise the statutes to ensure an individual's autonomy in making a decision to donate. SB 391 will provide clear language under that law that an individual who makes the decision to have their name added to the Kansas Registry has given their legal authorization and consent to donate specified organs and tissues. Most importantly, the technology will ensure that the information will be readily accessible to be acted upon at the time of their death.

As a result of improvements in information technology, donor-designated first person consent registries have been successfully implemented in approximately 42 states. Reliable, validated and easily accessed computer based registries are helping organizations like mine act on the legal wishes of people who have chosen to help others in need of a transplant by giving a gift of life. The passage of SB 391 will improve our ability to honor the donor's wish and help end deaths of those on transplant wait lists in Kansas and across the U.S.

Thank you for the opportunity to testify before the Committee today. I would be happy to answer any questions.

HEIN LAW FIRM, CHARTERED

5845 SW 29th Street, Topeka, KS 66614-2462

Phone: (785) 273-1441

Fax: (785) 273-9243

Ronald R. Hein

Attorney-at-Law

Email: rhein@heinlaw.com

**Testimony re: SB 391, First Person Registry
Senate Public Health and Welfare
Presented by Ronald R. Hein
on behalf of the
Midwest Transplant Network
January 26, 2010**

Mr. Chairman, Members of the Committee:

My name is Ron Hein, and I am legislative counsel for the Midwest Transplant Network, formerly the Midwest Organ Bank, a not-for-profit corporation designated by the Centers for Medicare and Medicaid (CMS) for the purpose of providing organ procurement services to hospitals.

I appear today on behalf of MTN to support SB 391, but I also appear today with a strong personal interest in this issue. I have experienced the Organ Donation System personally. As many of you know, my wife, Julie, gave me a kidney in September 1996 after I suffered kidney failure from end-stage renal disease (ESRD) caused by Type I (Juvenile) Diabetes. Diabetes is the leading cause of kidney failure.

I was fortunate that I had a live donor willing to donate this tremendous gift of life to me. Therefore, I was only forced to be on dialysis (in my case Continuous Ambulatory Peritoneal Dialysis (CAPD)) for 2 ½ months. Many victims of ESRD are required to be on either CAPD or hemodialysis treatment for extended periods of time, until a cadaver donor is available.

Unbeknownst to most people, many immunosuppressant drugs are a double-edged sword. While they help the individual fight the rejection of the kidney by suppressing the body's own immunological system so that they can keep a foreign organ in their body, taking the immunosuppressant drugs on a long term basis can also damage the donated organ. I had incurred some damage to my donated kidney as the result of the long term use of the immunosuppressants, specifically a drug called Cyclosporin, and I needed another kidney transplant.

Since I had had diabetes mellitus since 1964, instead of just undergoing another kidney transplant, I had decided to seek a combination kidney and pancreas transplant. Since I was obviously not eligible for a living donor, I was placed on the organ donation list.

In 2007, I successfully received both a kidney and a pancreas from a cadaver donor. Pursuant to this program, I received an organ donated by an individual who died, most probably as the result of a tragic accident, and the provisions of the Uniform Anatomical Gift Act (UAGA) were applicable to the donation and recipient process which was

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Date:

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utilized to provide this life sustaining procedure.

Therefore, I have more than just a professional interest in this serious issue before you today.

The first person registry will enable donors to register their wishes, and will provide a more effective mechanism for insuring that every person who desires to donate their organs can have their wishes recognized. This is not only good for fulfilling their wishes, but is also favorable for those victims who so badly need these life-sustaining organs.

Today, approximately 1,000 Kansans are waiting for an organ to be donated either by a live donor or under circumstances where a cadaver organ is available. Nationwide more than 83,000 men, women and children currently await life saving/enhancing transplants. An average of 17 people per day and 6,205 people per year die due to a lack of available organs for transplant.

The Kansas Legislature has an opportunity to help save lives with the passage of this legislation with no cost to the state. On behalf of the Midwest Transplant Network, and certainly on behalf of my family and me, I would strongly urge this committee to approve SB 391.

Thank you very much for permitting me to testify and I will be happy to yield to questions.