

MINUTES OF THE HOUSE APPROPRIATIONS COMMITTEE

The meeting was called to order by Chairman Melvin Neufeld at 9:00 A.M. on March 14, 2006 in Room 514-S of the Capitol.

All members were present.

Committee staff present:

Alan Conroy, Legislative Research Department
J. G. Scott, Legislative Research Department
Becky Krahl, Legislative Research Department
Matt Spurgin, Legislative Research Department
Debra Hollon, Legislative Research Department
Jim Wilson, Revisor of Statutes
Shirley Jepson, Committee Secretary

Conferees appearing before the committee:

Dr. Barbara Adkins, University of Kansas
Dr. Roy Jensen, Director, Kansas Masonic Cancer Research Institute
Mark Nelson, Executive Director, Kansas Masonic Foundation, Inc.
Jeanne Gawdun, Senior Lobbyist for Kansans for Life

Others attending:

See attached list.

- Attachment 1 Testimony on **HB 2988** by Dr. Roy Jensen
- Attachment 2 Testimony on **HB 2988** by Mark Nelson
- Attachment 3 Testimony on **HB 2988** by Jeanne Gawdun
- Attachment 4 Written testimony on **HB 2988** by Dr. Kathy Mitchell, University of Kansas
- Attachment 5 Amendment to **Substitute for HB 2245**

Representative Feuerborn moved to approve the minutes of March 1, March 2 and March 3, as written. The motion was seconded by Representative Pottorff. Motion carried.

Hearing on HB 2988 - Kansas cancer act, Kansas comprehensive cancer center, midwest cancer alliance, Kansas umbilical cord blood bank.

Deb Hollon, Legislative Research Department, explained that **HB 2988** creates the Kansas Comprehensive Cancer Center, consisting of the University of Kansas Cancer Center and other research programs at state universities and community colleges under the State Board of Regents. The Kansas Comprehensive Cancer Center will plan and develop an expanded, intensified and coordinated cancer research program for the benefit of all Kansans; Collaborate with and coordinate, through the Kansas bioscience authority, the cancer research efforts of all universities and community colleges, establish and provide for the operation of the Kansas umbilical cord blood bank, aggressively pursue effective initiatives to prevent cancer in humans, enhance access to exceptional cancer care and aggressively pursue translational and clinical research.

Chairman Neufeld recognized Dr. Barbara Adkins, University of Kansas, who introduced Dr. Roy Jensen, Director, Kansas Masonic Cancer Research Institute, to present testimony in opposition to **HB 2988** (Attachment 1). Dr. Jensen indicated that he is opposed to **HB 2988** because he felt it contained a number of important administrative and programmatic barriers for making the goal of establishing the cancer center a reality.

Responding to Committee questions, Dr. Jensen stated:

- The Exterior Advisory Board would advise in the process of applying for National Cancer Institute (NCI) designation.
- The University is currently in the process of creating and developing the structure of the board of directors. The board will be a self-governing group which lays out the research and

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- public health agenda for the Midwest Cancer Alliance.
- It is anticipated that the NCI application process will be completed by 2009.
- Currently working to move the program forward; requires a number of clinical trials.
- The Kansas State University cancer research program has had one grant from NCI in the amount of \$229,000. The program focuses on very basic research and looks at fundamental biology. Dr. Jensen indicated that they will work with Kansas State University and are particularly interested in working with the College of Veterinary Medicine.
- The idea for the KU Cancer Center started with dialogue from the Kansas Masonic Foundation, Inc. in the 1970's. Their recent pledge of \$15 million put the project on target. There also was a need for support from the University of Kansas which they know have.
- The Bioscience Authority is interested in the project; however, are not interested in taking the lead which also would be in direct conflict with NCI. The University of Kansas Cancer Center has to be the lead agency in order to get NCI designation.
- The Center will have approximately 50 unclassified employees, not all full-time.
- The withdrawal of the \$5 million from the State General Fund (SGF) could send a negative signal to NCI.
- The University of Kansas was approached by the Governor's office to develop a request for the appropriation and indicated that the project could be done without legislative oversight. It was also indicated that legislation was not necessary to move forward with the Cancer Center. They do not support the legislation unless it is developed in concert with the Director of the Cancer Center.
- The KU Cancer Center intends to provide detailed information on how the SGF appropriation will be spent and how future appropriations will be spent.
- There are presently 61 NCI designated cancer centers - 39 of these are comprehensive cancer centers. Presently, the closest cancer centers would be located in St. Louis or Denver.
- The No. 1 treatment of cancer at present is surgery; stem cell research and the Blood Cord Bank would not be effective in advancing the NCI designation. There would be a need for approximately \$3-\$4 million to set-up the cord blood bank. Dr. Jensen felt it needs to be a separate initiative.
- Would hope to align the hospitals across the state with the Midwest Alliance Board.
- Will provide a detailed breakdown on how the \$5 million State General Fund is budgeted to be spent.

The Committee noted the following issues that need to be addressed:

- Supports the concept; however, has a need to know the layout of the organization of the cancer center.
- Composition of the Board to be in compliance with NCI.
- A mechanism to provide for a long-term financial commitment from the Legislature and a procedure to allow for tracking of the State's commitment.
- Important to set up some protocol for the project.

The Chairman recognized Mark Nelson, Executive Director, Kansas Masonic Foundation, Inc., who presented testimony in opposition to **HB 2998** ([Attachment 2](#)).

The Chair recognized Jeanne Gawdun, Senior Lobbyist for Kansans for Life, who presented testimony in support of **HB 2998** and the establishment of a state umbilical cord blood bank ([Attachment 3](#)).

Written testimony was received from Dr. Kathy Mitchell, University of Kansas ([Attachment 4](#)).

The hearing on HB 2998 was closed.

Discussion and Action on Substitute for HB 2245 - Appropriations--Kansas fireworks act.

Representative Gatewood moved to amend HB 2245 by adopting the language contained in the Substitute Bill with the following changes: Striking language on Page 4, line 22 "in the past five years" and adding language to Sec. 3 (f) Page 3, Line 39 "no fee shall be charged for any person

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who is an officer or employee of the state or political or taxing subdivision thereof when that person is acting on behalf of the state or political or taxing subdivision" (Attachment 5). The motion was seconded by Representative Sharp. Motion carried.

Representative Gatewood moved to recommend **HB 2245** favorable for passage as amended and to report it as a substitute bill. The motion was seconded by Representative Feuerborn. Motion carried.

HB 3006 was referred to Education Budget Committee.
SB 569 was referred to Public Safety Budget Committee.

The meeting was adjourned at 11:00 a.m. The next meeting of the Committee will be held at 9:00 a.m. on March 15, 2006.



Melvin Neufeld, Chairman

**Testimony Before the House Committee on Appropriations
In Opposition to HB 2988
by Roy Jensen, MD
Director, Kansas Cancer Center**

Tuesday, March 14, 2006

Mr. Chairman and Members of the Committee:

I appreciate the opportunity to appear before your Committee again regarding the Kansas Cancer Center and our quest to develop a National Cancer Institute (NCI) designated comprehensive cancer center for the State of Kansas. I am grateful for the support that this Committee has demonstrated in supporting a \$5 million appropriation for building a world-class cancer center for Kansas.

Unfortunately the bill in front of you, HB 2988, contains a number of important administrative and programmatic barriers for making this goal a reality. Accordingly, I would request that you not advance this legislation. Today I would like to explain to you my reasons for opposing this legislation.

At the outset, I would like to remind the Committee that there are two significant components of our cancer plan that make us well qualified to attain comprehensive cancer designation – both of which are built on strong partnerships among important stakeholders throughout the State. First, is the creation of a drug development pipeline with the goal of discovering cancer cures and therapies. This pipeline will be developed in partnership with our basic science partners across the region. Second, is the creation of the Midwest Cancer Alliance, which will require that we collaborate with hospitals and provider groups across all of Kansas and the region to offer patients Phase I clinical trials and improved cancer prevention and screening.

Let me first discuss the drug development pipeline. HB 2988 contains several provisions aimed at ensuring coordination among the various stakeholders, such as making the Kansas Bioscience Authority the lead agency in coordinating cancer research efforts. We are hopeful that the Bioscience Authority will embrace and support the cancer center as an exceptional opportunity to develop the life sciences in Kansas. As part of attaining NCI designation, the development of the Office of Therapeutics, Discovery and Development at the University of Kansas is envisioned as an economic development dynamo where basic science is matched with opportunity for improving health and for enhancing economic vitality through commercialization. In addition, the cancer center will bring preeminent researchers to Kansas. It will lead all university efforts in the capacity to create new knowledge and distribute that new knowledge as intellectual property and products with commercial value.

However, the Bioscience Authority should *not* manage the cancer center's state appropriation for at least four reasons.

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First, resources are needed now. As the Bioscience Authority continues to thoughtfully determine its priorities, it would delay our efforts to build the basic infrastructure needed today for recruiting physicians and researchers, as well as applying for grant funding.

Secondly, I believe that with a \$5 million appropriation from the State, we already have a high level of accountability in place. The legislature reserves the ultimate power to determine if the money is well spent and if our performance justifies continued investment. In addition, we are reviewed by an External Advisory Board consistent with NCI guidelines. HB 2988 requires the creation of an executive advisory board, however, we already have a highly skilled advisory board in place, with ample NCI cancer center experience. And in terms of overall oversight, the Kansas Cancer Center adheres to the applicable rules and regulations required by the National Institutes of Health, the Food and Drug Administration, the Joint Commission on Accreditation of Healthcare Organizations, the accrediting body for the School of Medicine – the Liaison Committee on Medical Education, as well as the Board of Regents, the Governor's office, and the Kansas State Legislature.

Thirdly, NCI requires resources be managed by the cancer center director. According to the review criteria from the NCI, the cancer center director "*must have codified authority over (and effectiveness in the management of) the center's space and research resources, including: philanthropy, clinical revenues, or other revenue streams*" [<http://www3.cancer.gov/cancercenters/cetnersadmin.html> (page 39)]. Funding from the Bioscience Authority, while very important, would not be sufficient to justify designation from the NCI.

And lastly, but perhaps most importantly, the Kansas Cancer Center and the Kansas Bioscience Authority have differing missions, which equates to differing and sometime conflicting priorities. The ultimate mission for the cancer center is to end suffering and death from cancer and thereby improve the health of Kansans; the mission of the Bioscience Authority is to develop the life sciences for the purpose of driving economic development. Although there is clearly overlap in these goals, the cancer center must be able to manage its resources independently in order to focus first and foremost on the physical health of our citizens while the Bioscience Authority is free to focus on the economic health of our communities and state.

Next, let me address the issue of the Midwest Cancer Alliance. The design of our cancer center is not intended to create a fortress in Kansas City. Instead, the heart of our center is designed around a Midwest Cancer Alliance of health care providers, no matter where they live, to have access to world-class cancer screening, prevention, and Phase I clinical trials. We intend to create a Board of Directors – not an advisory board as the bill suggests – which will allow *all* MCA alliance members to have direct input into planning, implementation and oversight of the alliance. It will be critical that all members of the alliance have an equal opportunity for participation and sufficient flexibility is built into the MCA structure as we continue to fine tune its structure during its development.

Finally, I need to express the importance of the Kansas Cancer Center staying focused on the mission of cancer research. The final section of HB 2988 would establish an

Umbilical Cord Blood Bank, which falls significantly outside of the expertise and interest of our cancer center. According to the Director of the Bone Marrow Transplant Program and the Director of Laboratory Medicine and Clinical Laboratories at the University of Kansas Hospital, it is estimated that it would cost \$1million-\$2 million in startup costs to establish a public cord blood bank, plus operating costs of \$1,400-\$1,500 per unit collected. While the cost per unit could vary in time, at least initially the collection, testing, processing, cryopreservation and storage for 2,000 units could be as much as \$3 million to \$4 million. Since the legislation does not specify how this program would be paid for, it is reasonable to believe that you may be looking to the cancer center to provide funding. Such a diversion of funds from our core mission cannot be justified and would not, I believe, be looked upon favorably by the National Cancer Institute.

Additionally, from a governance standpoint the bills provisions could easily be construed as at odds with itself. The bill creates both an executive advisory board of the Kansas comprehensive cancer center in Section 4 and then creates a midwest cancer alliance governing board in Section 6 of the bill. This structure is contrary to the efficient and effective model we are developing and that is necessary to obtain NCI approval. While I appreciate the intent of those who crafted this legislation its actual provisions would have the affect of torpedoing much of the momentum this initiative has enjoyed to date.

And finally, while I hesitate to address Section 8 of the bill which would prohibit "lobbying or other activities to request or influence federal or state legislative action" I have to remind you that such a provision would preclude me from appearing before you on such matters as the one I address today. I believe the legislature can benefit from the input of members of the Kansas Cancer Center and I would not want to have a broadly worded statutory prohibition prevent such meaningful interactions from taking place in the future.

Although I do not support HB 2988 for the reasons described above, I cannot state strongly enough how important your support is in building a comprehensive cancer center for Kansas. The \$5 million annual appropriation is essential in providing for key infrastructure development and for leveraging other philanthropic funding. The entirety of the \$5 million will be strictly used for research and operations, as described in the attached document. Finally, I will personally deliver an annual report to the legislature describing how cancer center funds are used and progress being made toward achieving NCI designation.

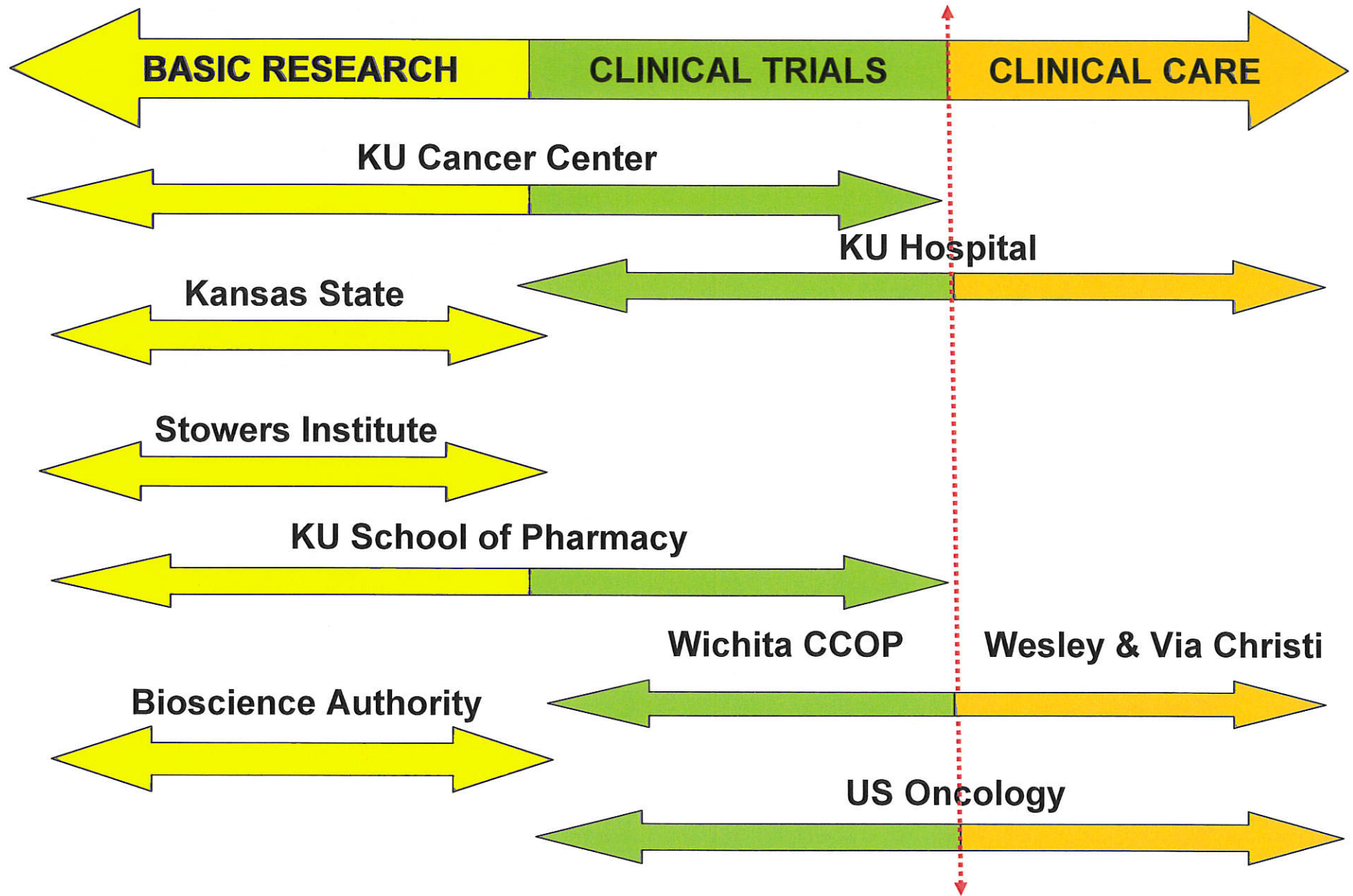
Please accept my gratitude for your interest in and commitment to ending cancer death and suffering in Kansas. I appreciate your leadership on this issue and I look forward to continuing to work with all of you as together we accomplish something important for the citizens we both seek to serve. I would be pleased to stand for any questions.

Respectfully submitted,

Roy Jensen, MD
Director, Kansas Masonic Cancer Research Institute
and The University of Kansas Cancer Center

1-4

NCI DESIGNATION



1-5

What Will \$5 Million Support?

Critical Need	Investment Required
Office of Therapeutics, Discovery and Development	\$ 391,000
Office of Clinical Trials and Affiliate Network	\$ 1,275,000
Pilot projects prior to grant funding	\$ 320,000
Start-up funds for newly recruited researchers/clinicians	\$ 800,000
Post-doctoral researchers	\$ 218,000
Shared resources for research technology support	\$ 686,000
Scientific Advisory Board	\$ 25,000
Director and senior leadership team	\$ 826,000
Administrative support	\$ 459,000
State Funding Requested	\$ 5,000,000

KANSAS MASONIC FOUNDATION, INC.



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**Testimony before the House Committee on Appropriations
In Opposition to HB 2988
by Mark Nelson
Executive Director, Kansas Masonic Foundation**

9:00 a.m., Tuesday, March 14, 2006

Mr. Chairman and Members of the Committee:

My name is Mark Nelson and I serve as the Executive Director of the Kansas Masonic Foundation. The Kansas Masonic Foundation was founded in 1966 and our first grant to the KU Medical Center's cancer program was in 1974. Although this gift was a small one, the Masons of Kansas had already realized the importance of the fight against cancer and were committed to assisting KU in their efforts. Since 1974, The Kansas Masonic Foundation has given a grant each and every year to KU's cancer program. By 2003 the Foundation had provided gifts totaling more than \$5 million.

In November 2003 the Kansas Masonic Foundation pledged an additional \$15 million to the Kansas Masonic Cancer Research Institute to support the translation of innovative and promising cancer research findings into clinical treatments and cures. This pledge brings the Kansas Masons' total giving to more than \$20 million to KU.

With this pledge, the KMF's goal is to help support research for improved treatments and cures for cancer. The KMF is excited about helping the KMCRI advance toward its ultimate goal of achieving National Cancer Institute designation—a goal that will not only benefit Kansans but everyone in the region. With this designation, Kansas City will join approximately 40 other U.S. cities as home to an elite, world-class, comprehensive cancer research and treatment center.

We are excited to work in this endeavor with Dr. Roy Jensen, a Kansas native and a brother Mason. We are confident that he is the right leader to take on this incredibly complex job and successfully guide this initiative to success. We strongly support the provisions in the budget you are now considering that would dedicate \$5 million in state appropriations to support the work of the cancer center. But, we must oppose any effort that we see as potentially damaging to our quest to secure NCI designation for the KMCRI. We believe HB 2988 does not advance and in fact diminishes the chances of the Kansas Masonic Cancer

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Research Institute receiving NCI designation. As such we would urge you to reject this legislation and advance the appropriation in support of the center without undue restrictions or delays.

Everyday we ask our 30,000 + members of the 275 Kansas Masonic Lodges and our friends to consider making a difference for their fellow Kansans by supporting the creation of a world-class cancer center here in our state. Today, we are asking you to join us and do exactly the same thing. We value Dr. Jensen's leadership and trust his judgment in developing a center worthy of NCI designation. He was part of the team that was successful in obtaining designation for the Vanderbilt University cancer center and we believe he must be given the resources, responsibility and authority to be successful here.

HB 2988 is unnecessary and we believe detrimental to moving our cancer center forward toward NCI designation and therefore we would ask that you not act favorably on the bill.

Thank you for this opportunity to appear before this committee.

Respectfully submitted,

Mark Nelson
Executive Director
Kansas Masonic Foundation



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Proponent HB 2988

March 14, 2006

House Committee on Appropriations,
Chairman Melvin Neufeld

Good morning, Chairman Neufeld and members of this committee, I am Jeanne Gawdun, senior lobbyist for Kansans for Life, affiliate of the National Right to Life Committee. Our organization urges Kansas to become a leader in bio-science that is ethical as well as productive. That is why I am very happy to be here today to voice our support for HB 2988, which will set up a state umbilical cord blood bank.

Cord blood refers to the contents of an umbilical cord, safely collected following delivery of a newborn. Cord blood is a rich source of stem cells that can be used to treat over 70 diseases, including sickle cell disease, a crippling, and mostly fatal, disease affecting African-Americans. Minorities have had more difficulty finding bone marrow donors for a variety of reasons (see attached information.) In place of bone marrow, cord blood can be used for transplantation with an easier "match" found between a patient and non-family donor, and a lower risk of immune reactions.

Cord blood collection poses no risk to mother or baby, and is stored frozen ready for quick access. Unlike the hyped and unrealized treatments from embryonic stem cells, cord blood can be utilized in Real Cures for Real People. The recent passage of the federal Bone Marrow and Cord Blood Act now enables Kansas to get in on the ground floor of this important medical service.

Because this medical specialty is rapidly evolving, we would suggest that that the public banking of this cord blood also include the banking of the cord itself, and any other medically valuable neonatal cell products, in appropriate partnership with the public.

Please also consider broadening the language in section 5 to accommodate a full public service education campaign about the ease and merits of free donation and free utilization of such a blood bank. Please pass this bill out of committee and make this service a reality. Thank you.



Kansas Affiliate of the National Right to Life Con

With over 50 chapters across the state of Kansas

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When 5-year-old Gina Rugari started kindergarten in Cincinnati this fall she brought her own crayons, pencils, glue sticks and pink backpack, but the blood flowing through her arteries was not her own. Her red and white cells are the result of an umbilical cord blood transplant she had at 3 weeks of age. The transplant from an unrelated donor repopulated her bone marrow with stem cells, the wellspring of her new blood supply. Her blood does all the things blood is supposed to do, but in Gina's case it does something much more: It prevents the swift destruction of her brain by a faulty gene she was born with.

Medical Hope in Umbilical Cord Blood Healing Powers May Provide Cures for Many Deadly Maladies

October 23, 2005 By Ronald Kotulak, Science Reporter Chicago Tribune



What is proving to be a lifesaver for Gina is also turning out to be a medical treasure trove for scientists. Cord blood is surprising researchers with previously unrecognized healing powers that go far beyond its known effectiveness against childhood leukemia and some other disorders. Yet despite growing efforts to encourage parents to donate cord blood to banks that freeze and store it for possible future use for their child, or for other patients in need, most of the blood is still discarded after birth.

Gina's condition, a rare **genetic defect called Krabbe disease, is the latest entry on the list of illnesses for which cord blood is effective**. Others range from leukemia and sickle cell disease to aplastic anemia and immunodeficiency diseases. Early research in animals suggests that cord blood may provide a new bounty of cures and treatments for many other medical conditions, including heart attack, Parkinson's disease, stroke, Alzheimer's disease, muscular dystrophy, diabetes, spinal cord injury and amyotrophic lateral sclerosis.

"This is all new biology, which could have an unlimited potential," said Dr. Paul Sanberg, director of the University of Southern Florida's center for aging and brain repair. "Cord blood research is moving us into an era of regenerative medicine where we're going to be approaching chronic degenerative diseases with ways to repair them by generating new tissues."

All of this was unanticipated in 1990 when the University of Minnesota's Dr. John Wagner performed the first cord blood transplant, a risky procedure then that everyone said wouldn't work. His boss told him to stop the research, saying it would never be of any use. "Now we're seeing that it's a potentially untapped resource," said Wagner, who plans to start clinical trials next year using cord blood to treat autoimmune diseases. "What we have seen so far may be only a drop in the bucket." ...

Cord blood does not have to be perfectly matched, because the immaturity of a newborn's immune system means the white blood cells are less likely to attack the transplant recipient. To treat children with a life-threatening genetic defect, their own bone marrow is chemically destroyed to make room for blood-making donor stem cells. The donor cells home in on the patient's marrow, where they produce a healthy new supply of blood that contains the vital enzymes the children lack. The stem cells also migrate to the brain and other areas of the body, where they take up residence to supply damaged cells with the enzymes and proteins they need to build myelin, snuff out inflammation, battle infection, spur growth and in other ways restore and maintain the health of cells.

Virginia backs statewide umbilical cord blood bank Jan.18, 2006

Richmond: A House of Delegates committee endorsed legislation establishing a statewide banking system for umbilical-cord blood that would aid cancer treatment and stem cell research. **Cord blood is used primarily to treat childhood cancers, including leukemia, but it also could be used to prevent leukemia caused by radiation of terrorists attack with a nuclear "dirty bomb."**

The bill directs the state health commissioner to establish the consortium, working with medical schools, hospital systems, biotechnology companies, regional blood banks, laboratories and others. The commissioner also would develop a system for informing pregnant women about umbilical cord blood donations and obtaining their consent for harvesting the blood. 3 states - Florida, Massachusetts and New Jersey - and the governments of several foreign countries support cord blood banking. Virginia's bill would establish a storage capacity of at least 40,000 doses.

What is cord blood? After a baby is born and the umbilical cord is cut, some blood remains in the blood vessels of the placenta and the portion of the umbilical cord that remains attached to it. After birth, the baby no longer needs this extra blood. This blood is called placental blood or umbilical cord blood: "cord blood" for short.

Cord blood contains all the normal elements of blood - red blood cells, white blood cells, platelets and plasma. But it is also rich in hematopoietic (blood-forming) stem cells, similar to those found in bone marrow. This is why cord blood can be used for transplantation instead of bone marrow.

Cord blood is being used increasingly on an experimental basis as a source of stem cells, as an alternative to bone marrow. Most cord blood transplants have been done to treat diseases of the blood and immune system. It has also been used to restore the functional deficiencies of several genetic metabolic diseases. To date, more than 70 different diseases have been treated with cord blood transplants.

Cord blood success. So far, more than 6,000 patients and 66 diseases have been successfully treated with **neonatal cord blood** stem cells, including hematological malignancies such as leukemia and lymphoma; the immunodeficiency diseases SCID, CID, CVID, and WAS; bone marrow failure syndromes; hemoglobinopathies such as **sickle cell anemia** and thalassemia major; and inborn errors of metabolism such as ADL, MLD, GLD, Tay-Sachs disease, and MPS I, II, III, and IV.

Because stem cells from cord blood don't cause nearly as much graft versus host disease, they **do not need a perfect match the way bone marrow does**; as a result, a national inventory of only 150,000 ethnically diverse cord blood stem cell units will provide 80 percent of U.S. citizens with a suitable match.

Julius "Dr. J" Erving joins bi-partisan push for cord blood banking

Date: Oct. 6, 2005 **Location:** Washington,DC Cord blood recipients and Julius "Dr. J" Erving joined

members of Congress from both sides of the aisle to urge the Senate to pass S-1317, Bone Marrow and Cord Blood Therapy and Research Act of 2005. *(Jamie Rose/US Newswire)*



"Many Black kids who suffer from sickle cell may go to doctors who don't know much about cord blood," says bill cosponsor Rep. Artur Davis (D-AL). "This legislation will help doctors point patients to available units of the blood." This bill became law in December.2005.

Why is cord blood important for ethnic minorities?

Many patients who need a bone marrow transplant cannot find a suitable donor - no relative that matches and no match among volunteer bone marrow donors. There are differences in the frequency of certain blood antigen (HLA) types among ethnic groups. Therefore, patients are more likely to find a good match among donors from their own ethnic group. **African-American patients who need bone marrow transplantation have an especially hard time finding an unrelated bone marrow donor.** There are three reasons for this difficulty. The first is simply numerical. African-Americans make up only 12% of the U.S. population and, thus, fewer potential donors are available. The second reason is that there is much greater variation in HLA-types among people with African ancestry than in any other group. And third, some people who have both African and European or other ancestry have combinations of the HLA types that are unique.

It is estimated that at least three times as many African-American volunteer bone marrow donors than Caucasian donors would be needed for African-American patients to have a chance that equals that of Caucasian patients to find a match among bone marrow donor registries. As a result, African-American patients are much less likely to find a matched, unrelated bone marrow donor. **With cord blood, however, a partial match is acceptable and most African-American patients can find a suitable cord blood unit.** Large public cord blood bank inventories, therefore, can make up for the difficulty in finding suitable bone marrow donors for minority patients.

2002 US Government Accounting Office Report:
Estimates for Bone Marrow Transplantation (1997-2000)

Ethnic Group	Percent of Patients Seeking a Bone Marrow Donor	Percent of Donor Volunteers* Registered in NMDP	Percent of Patients Receiving Bone Transplant Facilitated by NMDP
Asian	3.7%	8%	2.4%
African-American	12.1%	10%	6.3%
Hispanic	12.5%	11%	7.6%
Caucasian	69.1%	67%	81.9%

*Donor ethnicity known

2002 GAO Report
(National Marrow Donor Program May Be Underutilized)
"... equal access to a transplant may not be attainable."

African-Americans, like everyone else, need transplants for leukemia, lymphoma, and inherited diseases such as severe combined immune deficiency (SCID or "boy-in-the-bubble" syndrome). In addition, African-Americans are more likely than others to suffer from sickle cell disease, a sometimes devastating and crippling disease that eventually will be lethal for most patients. At present, the only cure is a transplant. Patients from other ethnic minority groups also have more difficulty finding a matching unrelated bone marrow donor. Again the problem is numerical. Minority groups simply have smaller numbers from which to draw potential donors. Many Hispanic patients also have ancestry from more than one ethnic group. People from different regions of Asia also tend to differ in their HLA types.

What are the advantages of cord blood?

1. Cord blood collection is easy and poses no risk to mother or baby.
2. Cord blood is collected in advance, tested and stored frozen, ready to use.
3. Cord blood doesn't require a perfect match.
4. Cord blood poses fewer risks of certain complications to the recipient. The immune cells in cord blood seem to be less likely than those in bone marrow from unrelated donors to attack the patient's own tissues (graft vs. host disease). Cord blood is also less likely to transmit certain viruses.



The first patient to receive a cord blood transplant from an unrelated donor for sickle cell disease was Keone Penn (pictured here with his mother, Leslie).

Born with severe sickle cell anemia (a disease that afflicts more than 70,000 Americans and a disproportionate number of African-Americans), Keone Penn suffered a stroke at age five and endured frequent episodes of pain throughout his childhood. He received regular blood transfusions through a chest catheter for his anemia, Keone continued to have pain crises, bone and joint crises and developed kidney complications.

Keone's doctors began considering a stem cell transplant as a last resort. Keone's sister, a possible bone marrow donor, failed to match and no unrelated bone marrow donor match was found. Keone's doctor, Andrew Yaeger (now at the University of Pittsburgh), decided to try transplantation with cord blood from an unrelated donor, the first time this had been tried for sickle cell disease.

At Egleston Children's Hospital (now the AFLAC Cancer Center of Children's Healthcare of Atlanta), Keone underwent nine days of chemotherapy to eliminate his own defective bone marrow cells. On December 11, 1998, Keone got cord blood from a healthy donor to the New York Blood Center's National Cord Blood Program. His recovery was long and, at times, extremely difficult. He was readmitted to the hospital several times, and nine months after the transplant he developed graft vs. host disease (GvHD) as his newly transplanted cells began to attack his own body.

Eventually, these complications subsided. Keone's new stem cells now produce normal red blood cells with normal hemoglobin. The swelling in his joints has subsided and Keone has not had one further pain crisis. On the one-year anniversary of his transplant, Keone's doctor pronounced him cured. Keone graduated from high school in 2004 and plans to train as a chef in culinary school.

"I want to hug the man who thought of it," Keone told an Atlanta Journal-Constitution reporter before a banquet honoring cord blood transplant survivors held in 2003. "I just want to give him a big hug and break his ribs and squeeze him so tight." http://www.nationalcordbloodprogram.org/patients/patient_keone.html

Given at a Science, Technology, and Space Hearing Thursday, June 12 2003
Hearing on Advances in Adult and Non-Embryonic Stem Cell Research

The Testimony of Mr. Keone Penn ,

My name is Keone Penn. Two days ago, I turned 17 years old. Five years ago, they said I wouldn't live to be 17. They said I'd be dead within 5 years. I was born with sickle cell anemia. Sickle cell is a very bad disease. I had a stroke when I was 5 years old. Things got even worse after that. My life has been full of pain crises, blood transfusions every two weeks, and more times in the hospital than I can count. The year before I had my stem cell transplant, I was in the hospital 13 times. I never was able to have a normal life. My stem cell transplant was not easy, but I thank God that I'm still here. I will graduate from high school this year. I want to become a chef because I love to cook. I think I'm pretty good at it. Sickle cell is now a part of my past. One year after my transplant, I was pronounced cured. Stem cells saved my life. Thank you.

.Kansans for Life supports HB 2988, creating cord blood banking in Kansas.

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Public Cord Blood Bank needed in Kansas

HB 2988 would fund a state bank for collection of umbilical cord blood, utilizing the new federal law enacted in December. Cord blood donated to a public bank provides another source of hope for patients who have no matching donor in their own family, no unrelated donor in bone marrow donor registries that is a suitable match or no time to find a donor.

Umbilical Cord Blood Stem-Cell Transplant Saves Sickle Cell Diseased Teen's Life Many Parents Banking Umbilical Cord Blood

November 28, 2001 (60 Minutes/CBS) Stem cells are thought of as the Holy Grail of medicine. One young boy agrees with that. He made medical history because he's been cured of his life-threatening disease. The key to his cure did not come from a human embryo, where all the controversy is, but from something that is routinely tossed in the garbage - an umbilical cord. Umbilical cords were always considered medical waste. Not anymore. Correspondent Carol Marin reports.

That's why new parents like Pam Dorne and Stephen Ayers of suburban Chicago have decided to save their children's umbilical cord blood. Dorne gave birth last spring to a baby boy, Kyle. After a baby is born, there is just a 15-minute window to retrieve the four to six ounces of blood in the umbilical cord. And in that blood are potentially lifesaving stem cells that can be saved for future use.

This is really where, I think, so much of biomedicine is going to be going in the 21st century," says Dr. Andrew Yeager of the University of Pittsburgh. For instance, **when stem cells from umbilical cord blood are injected into a person's vein, they migrate to the bone marrow and can create what Dr. Yeager calls a blood factory, replacing diseased blood with healthy blood.** According to the National Institutes of Health, stem cells may one day be able to repair the body's tissue and muscle and cure everything from spinal cord injuries to Alzheimer's.

It's not just pie-in-the-sky speculation," says Yeager. There are studies that would suggest that other organ dysfunction - nerve damage, heart damage, brain-cell damage - might actually be fixed." It has the potential to make paralyzed patients walk and make Alzheimer's sufferers remember. That potential is what Dr. Yeager was counting on to cure a young patient named Keone Penn.

Keone suffers from a case of sickle cell, a painful genetic blood disease. He was diagnosed when he was 6 months old. He was 5 when his sickle cell caused a stroke. The odds were that Keone had, at best, only five years to live. So Yeager decided to take a chance on a new procedure. Never before had stem cells from umbilical cord blood been used to treat sickle cell.

The goal here is that **these stem cells, which are in a relatively high proportion in cord blood** - higher than they would be in our own bone marrow and definitely higher than in our own circulating blood - could then be injected and would take hold and again, make more of themselves. And make a whole new blood factory."

Ordinarily, patients with a severe case of sickle cell, like Keone's, would have had a bone-marrow transplant. That's because until recently bone marrow was the only source for stem cells. (continued>)

But bone marrow transplants can be tricky because there must be a precise match between the person donating the bone marrow and the patient receiving it. In Keone's case, no match could be found.

Stem cells from umbilical cord blood don't need an exact match. Dr. Yeager and his team found a match that was close enough in a cryogenic tank at the New York Public Blood Bank, which since 1992 has slowly been collecting donations of umbilical cord blood

Over Christmas vacation of 1998, after intensive chemotherapy to destroy Keone's bad blood, he was injected with the stem cells. After a few weeks, something extraordinary happened - the stem cells changed his entire blood system from type O to type B. That concept there is the one that really blows my mind," says Leslie Penn. The thought that your whole blood type is changed. The umbilical cord cell's donor, he took on their blood type.

A year later, doctors declared that the sickle cells in Keone's body had disappeared. Today, he is considered cured. **It was umbilical cord stem cells that cured Keone, not stem cells from human embryos.**

While the use of embryonic stem cells has generated fierce controversy, umbilical cord stem cells have attracted little attention and no political debate. And now it seems, more and more new parents have decided to bank their hopes on the stem cells in their newborn's cord blood.

So far, Cord Blood Registry has collected about 30,000 samples from families willing to pay a \$1,300 flat fee and \$95 a year to analyze and privately store their baby's cord blood. The company has taken in over \$40 million so far, selling a kind of biological insurance. Part of the issue when people bank," says Harris, it is because they have a family history or they work or live in a place where there is a potential for cancer. But part of it is for peace of mind."

According to the American Academy of Pediatrics, that peace of mind isn't worth the money. The academy says **the chances a family will ever need to use its frozen cord blood are very small. What they say makes more sense is to donate cord blood to a public bank**, the kind where Keone Penn got his stem cells. What saved Keone Penn's life, Dr. Yeager says, is a public blood bank and the umbilical cord blood from an anonymous donor. If they wish to pay, that's absolutely fine." He says of patients. But to look at a larger, greatest good for greatest number, I would contend that a volunteer donation to a public blood bank would make the most sense."

Meanwhile, Keone, a pioneer, is doing things he's never done before. I discovered the other day that I like playing basketball, Keone says. I never played basketball, 'cause I've always been disabled to play it and to have fun." Keone, who one day hopes to become a chef, still has some major health problems as a result of infections that occur in most stem-cell transplants. Because of steroids and other medication, he has arthritis, walks with a limp and will need joint replacement in his hips and knee. But the good news is the sickle cell that was killing him is gone. I love stem cells," he says. I mean they saved my life. If it weren't for them I wouldn't, you never know, I probably wouldn't be here today."

Keone doesn't know where the cord blood came from or who is the owner. He says he would like to know, just so he could say, Thank You." http://www.cordblood.com/cord_blood_news/stem_cell_news/article_60minutes.asp

Kansans for Life supports HB 2988, creating cord blood banking in Kansas.

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March 14, 2006

Chairmen Neufeld,

First of all, I apologize for not being able to attend this meeting to provide this testimony in person. My mother has been hospitalized and with a mild heart attack and I need to be with her tomorrow while she undergoes tests. I also want to emphasize that the opinions and perspectives in this testimony are my own and do not represent official policy of the University of Kansas or the views of university administration.

Umbilical cord blood banking consists of the collection, processing, and preservation of the blood (containing stem cells) within the umbilical and placental circulation shortly after delivery of an infant. This process is not harmful to either the mother or to the newborn child as these tissues are routinely discarded. There are several options for parents today for banking umbilical cord blood. See Figure 1. Private banking is the most common and is paid for by the parent and the cells are only available to the child or a family member. This is costly and paid for by the parents. These cells are not available to other recipients for whom they could be life-saving in cancer therapies or to researchers. There are also now public banks but none in the state of Kansas. This type of donation is done at no cost to the parent and the cells can be used either for cancer therapy or research. There is a window of time which is important for successful retrieval of the stem cells, so having a stem cell bank in Kansas would provide a significant improvement for donations.

Types of Cord Blood Banks

	Private bank	Transplant public bank	Research public bank
Parent cost	\$900-\$1800	Free	Free
Blood owner	Parents	Bank	Bank
Bank income	Parents	Med. Ins. & Sales	Sales & Patents
Blood usage	Parental discretion	Transplants & Research	Research

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Umbilical cord blood has been used since the 1980's in bone marrow replacement therapy when adult stem cell donors that match the recipient's blood type couldn't be found. This is feasible because of one of the remarkable properties of umbilical cord blood is that it is less likely to cause on condition known as graft versus host disease where the new cells attack the recipient's organs, which is often fatal. This property of umbilical cord blood makes it a uniquely useful source of potentially life-saving cells. Umbilical cord blood is commonly used in cell-based therapies today for reconstitution of the bone marrow after radiation for cancers of the blood. There are some new experimental therapies using umbilical cord blood cells being developed for other diseases. Umbilical cord blood transplantation in Wiskott Aldrich syndrome (bubble boy syndrome), which results in severe immune deficiency and early death without treatment, results in rapid and reliable recovery of immune function, with low risk of graft versus host disease. Using umbilical cord blood stem cells taken from unrelated donors, to treat children with Hurler's syndrome resulted in improved survival and minimal loss of IQ, which is typically seen in untreated Hurler's patients. Stem cells from cord blood may have special properties that allow them to cross into the brain more effectively than stem cells from adult sources like bone marrow. Research is currently underway to expand the use of umbilical cord blood cells to treat blood disorders like sickle cell anemia.

Animal models suggest that umbilical cord blood cells may be useful in treatment of amyotrophic lateral sclerosis (Lou Gerhig's disease) and may slow motor neuron degeneration which helps to maintain muscle control. Umbilical cord blood cells could extend the survival of several mouse models of human disease including Lou Gerhig's disease, Alzheimer's; Huntington's, Parkinson's and type 1 diabetes. Human umbilical cord blood cells also improve the mobility of rats with spinal cord injuries. Similarly, umbilical cord blood cells were able to improve function in a stroke model in the rat. This suggests that umbilical cord blood cells potentially have a broad ability to heal neurological diseases and injuries.

There is enthusiasm in the potential of umbilical cord blood as a source of multipotential stem cells. The ability to expand the umbilical cord blood cells once they are harvested makes them unique from adult blood or bone marrow. They can also be stored in a frozen state indefinitely. These properties of umbilical cord blood, in addition to their potential to contribute to repair of other tissues, demonstrates their potential for future stem cell-based therapies. Stem cells from umbilical cord appear to have the unique ability to evade the immune system which makes their use therapeutically particularly exciting

Other types of multipotential stem cells can be harvested from umbilical cord matrix (the tissues that surround and cushion the umbilical cord blood vessels), amniotic fluid and placenta. The cells from umbilical cord matrix have been shown to be particularly exciting and research done at Kansas State and the University of Kansas has gained much national attention. This work has the potential to develop into cell-based therapies that can save lives or improve the quality of life of many individuals as well as to have agricultural applications.

The key factor for stem cell therapies to fulfill the promise that they hold is to have readily available sources of cells. Umbilical cord cells are needed for the treatment of cancer where they have already been demonstrated to be a life-saving therapy for thousands. Readily available sources of umbilical cord, umbilical cord blood, placenta and amniotic fluid stem cells are also needed by researchers to study their potential in other therapeutic applications which is the ultimate goal of biomedical research.

Best regards,

Kathy E. Mitchell
Assistant Professor of Pharmacology
Founding Fellow of the Midwest Institute for Comparative Stem Cell Biology

Amendment to HB 2245

Page 4, line 22 - strike the words "in the past five years"

This would be consistent with statues for possession of a weapon/firearm.

Technical change to effective date of this act January 1, 2007.

Sec. 3 (f) line 39 of page 3.

no fee shall be charged for any person who is an officer or
employee of the state or political or taxing subdivision
thereof when that person is acting on behalf of the state or
political or taxing subdivision.

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