Midwest Stem Cell Therapy Center

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The Distinguished Chair and Honored Members of the Committee.

Thank you for the opportunity to testify on this important topic. I testify in <u>SUPPORT of SB 199</u>.

I am a cell biologist, currently working for a policy think tank in Washington, D.C. and as an adjunct professor at a local university. For the previous 20 years, I was Professor of Life Sciences at Indiana State University and Adjunct Professor of Medical & Molecular Genetics at Indiana University School of Medicine, and I have done federally-funded laboratory research, lectured, and advised on these subjects extensively, in the U.S. and internationally. I was selected by the Bush President's Council on Bioethics to write the comprehensive review of adult stem cell research for the Council's 2004 publication "Monitoring Stem Cell Research". I am also a native Kansan, born in La Crosse, Kansas, raised near Parker, Kansas, with my degrees from the University of Kansas.

We've previously discussed in the joint committee hearing of Feb. 7 and 8, how there is a 1 in 200 chance that you or I, or anyone living in the U.S., will undergo an adult stem cell transplant during our lifetime. You've heard testimony from doctors as well as patients about some of the amazing adult stem cell and cord blood stem cell treatments that are ongoing, some that are on the way, and the need for much more in the way of patient treatments, as well as accessibility and education for both physicians and patients about current and potential stem cell treatments. As you heard in prior testimony, those successful treatments include published reports on autoimmune diseases such as multiple sclerosis and juvenile diabetes, heart damage, stroke, blindness, spinal cord injury, and cancer. There are significant opportunities right now for Kansas to take a leading role in this medical revolution and for Kansans to benefit from the establishment of a center of excellence specializing in the application of adult stem cell therapies for certain diseases, as well as educating physicians as well as the public about the advantages and availability of stem cell treatments.

There is now before you a proposal to make this a reality. SB 199 proposes establishment of the Midwest Stem Cell Therapy Center. The Midwest Stem Cell Therapy Center will be primarily focused on patients. The goals as listed, all nine, are all related to advancing and delivering adult and cord blood stem cell therapies to patients and serving as a resource for adult and cord blood stem cells for therapies, as well as informing professionals and the public about such therapies. Even in terms of the research aspects, the objectives of the Center will be to expand access and increase the range of stem cell treatments available to Kansans and others in the region. Adult and cord blood stem cells are the only proven successful stem cell for patient therapies. Currently over 60,000 people a year around the globe receive adult stem cell transplants for dozens of different conditions. Application of adult and cord blood stem cells for clinical therapy is an area that is rapidly blooming, and the Center can make Kansas a focal point for such therapies as well as for education and training.

¹ Nietfeld JJ et al., Lifetime Probabilities of Hematopoietic Stem Cell Transplantation in the U.S., Biology of Blood and Marrow Transplantation 14, 316-322, 2008

There is a significant education and training aspect to the proposed Midwest Stem Cell Therapy Center. Many physicians are unaware of the availability of existing stem cell therapies, or clinical trials that could benefit their patients. The public is also often uninformed regarding adult stem cell treatments. The Center can serve as a resource and training facility for physicians. This can include as a core facility to produce clinical-grade stem cells for treatments, forming a network of physicians and scientists using adult stem cells for therapies and developing new and improved therapies, coordinating clinical trials and research projects, and training physicians in adult and cord blood stem cell applications.

To educate physicians and the public about applications of adult and cord blood stem cells and availability, the Center will create education modules for physicians and scientists. Similar education modules can be created for elementary, secondary, and university students as well, so that students at all levels receive accurate information regarding stem cell therapies. Public education will also be an aspect of the Center's mission, potentially including town halls, community forums, newsletters, and public service announcements.

One key educational aspect for the Center will be creation and maintenance of a database resource regarding available validated stem cell therapies and clinical trials. No such database now exists. The clinicaltrials gov database maintained by the NIH and FDA of approved trials only meets part of this goal; a manual search using specific terms shows that over 2,600 clinical trials using adult stem cells for patients are listed,² but the database itself is not specifically focused on adult and cord blood stem cell trials or treatments, and there are no ongoing verifications nor alerts when any new trials are started. The Center's database would provide a unique global resource for physicians and patients.

The proposal also provides for an Advisory Board to assist and advise the Director of the Center. Advisory Board members, who would serve without compensation, would provide guidance to the Director and also might be asked to help in fundraising and in various public relation capacities to inform and excite the public about the Center and advancing its mission. The Advisory Board is proposed to consist of 13 members from a broad representation of stakeholders across the state and even the nation. The Director would serve as an ex officio member. The Director is given latitude on how to implement the mission of the Center. One important requirement is that the Director have both clinical and research background and experience regarding adult and cord blood stem cells, so that the person responsible for guiding the mission of the Center has the necessary skills for all aspects of its administration and coordination.

Kansas is moving forward as a potential leader in the area of adult and cord blood stem cell therapies. Estimates are that KU Med has done over 1,000 adult stem cell transplants, from bone marrow as well as a growing number from umbilical cord blood. These include stem cell transplants for various cancers and leukemias,³ but also initiating clinical trials to treat heart damage. So much more is possible.

The Midwest Stem Cell Therapy Center would be relatively unique. Most "stem cell centers" focus on basic research with no clinical component. Those labeled "stem cell treatment centers" tend to emphasize certain clinical treatments but do not educate the public or physicians. The proposed Midwest Stem Cell Therapy Center would coordinate clinical therapies and research, as well as basic research and education of physicians and the public, serving as a unique global resource.

Kansas is well-positioned to become a leader in this area, and a unique global resource. The potential benefits for patients are incalculable. I urge you to support SB 199.

 $^{^2 \} Search \ term: \ \underline{http://www.clinicaltrials.gov/ct2/results?term=adult+stem+cell+transplants\&type=Intr} \ accessed \ Mar \ 17, \ 2013.$

³ See, e.g., http://www.stemcellresearchfacts.org/adult-stem-cells-mary-lou/