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Representative David Crum, Chair
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Mister Chair and distinguished Members of the Committee, my name is John F. Morris. I am an ethicist active in the public discourse of issues in medical and bioethics, with a special focus in the area of adult stem cell research for more than a decade. It is an honor and privilege to have the opportunity to provide this testimony to you today in support of **Senate Bill 199** to establish **The Midwest Stem Cell Therapy Center at the University of Kansas Medical Center** which would serve as a hub for adult stem cell treatments, information, and medical networking.

The potential and promise of adult stem cell research has been well established through an impressive body of published medical research and is currently being investigated in numerous, ongoing clinical trials. The other medical and scientific experts providing you today with oral and written testimony can speak to the successes of adult stem cell research more directly than I.

For my part, I follow the published medical research involving adult stem cell trials very closely so that I can share accurate and up to date information with members of the community in my public role as an ethicist. It is an area of research in which people are keenly interested, and I have given well over a hundred presentations to civic groups all over the Kansas and Missouri region in the last ten years on the topic of adult stem cell research.

In these presentations, in order to personalize this growing field of research, I like to present stories of actual patients who have been treated with adult stem cells. For example, I tell the story of Joseph Davis, Jr., of Cedar Hills, Texas, who was born with sickle cell anemia and cured in 2002 using a procedure that relied in part upon an adult stem cell transplant using umbilical cord blood that came from Joseph's own newborn brother, Isaac. Today, Joseph and Isaac tour the country with their parents telling their story in order to raise awareness about establishing umbilical cord blood banks for future research and treatment. (<http://www.cordblood.com/benefits-cord-blood/our-clients-their-stories/cord-blood-banking-reviews/sickle-cell-anemia-treatment>)

I also share the story of Barry Goudy, who was diagnosed in 1995 with Multiple Sclerosis. His MS progressed rapidly, and in 2003 Barry underwent a procedure to treat his disease that included a transplant using his own adult stem cells. He has been in remission from his MS since his adult stem cell treatment, and has returned to an active lifestyle which includes coaching youth hockey. ("Adult Stem Cells May Treat Many Diseases Study Suggests Benefits for Patients With Autoimmune Diseases and Heart Disease," by Salynn Boyles, WebMD Health News Feb. 26, 2008, <http://www.webmd.com/rheumatoid-arthritis/news/20080226/adult-stem-cell-therapy-shows->

promise. See also Barry's recent YouTube Video testimonial at:
<http://www.youtube.com/watch?v=8PZEzVCudhs>).

There is also the story of Nathan Mumford who was diagnosed with leukemia shortly after he graduated from college. In 2004, unable to find a bone-marrow match for treatment, Nathan was told by his doctors that he could continue with low-dose chemotherapy, which at best would give him about another year and half to live, or he could try an umbilical cord blood transplant – a new approach for treating adults needing stem cell transplants. In 2010, at the age of 30, Nathan was featured in a CNN story highlighting his successful treatment and his efforts to raise awareness among minorities about adult stem cell research. (“Cord blood stem cells help meet minority marrow needs,” by David Martin, CNN March 2, 2010, at:
<http://www.cnn.com/2010/HEALTH/03/01/cord.blood.marrow.minorities/index.html>)

People are also amazed at the story of Roland “Bud” Henrich who in 2009, at the age of 61, arrived too late at the Texas Medical Center after having a stroke to receive tissue plasminogen activator (tPA), the only treatment for ischemic strokes. After consultation, Bud was enrolled in a clinical trial at the Center which offered an experimental treatment using his own bone marrow stem cells. When he first arrived at the hospital, Bud was unable to speak and had severe weakness on his right side. When he was released two weeks later, he was able to walk unassisted, climb stairs on his own, and spoke his first words since the stroke. (“Stroke Patient’s Own Stem Cells Used In Trial For First Time,” <http://www.sciencedaily.com/releases/2009/04/090415162654.htm>).

I also get a lot of interest in the story of 80 year old Helen Thomas of Hastings, Michigan, who was facing a leg amputation due to poor circulation as a result of peripheral arterial disease. She elected to participate in a clinical trial that used a transplant of adult stem cells, which have been shown to help in the growth of new blood vessels around clogged portions of arteries. Helen was one of six patients in the trial able to avoid amputations. (“New Study Uses Adult Stem Cells In Effort To Save Limbs Of Patients With Peripheral Arterial Disease,” 12 Feb 2010, at:
<http://www.prnewswire.com/news-releases/new-study-uses-adult-stem-cells-in-effort-to-save-limbs-of-patients-with-peripheral-arterial-disease-84104197.html>).

Finally, in the last few years I have included the story of a local family who have been twice blessed by adult stem cell research. Jenni and Daniel Bayless of Bolivar, Missouri, found out in March of 2008 that their first child, Granton, had been born with Severe Combined Immunodeficiency Disease (SCID), a rare genetic disorder in which the immune system does not develop. In order to treat the condition, more commonly referred to as bubble boy syndrome, Granton was given an umbilical cord blood transplant to help grow him a new immune system. The procedure was done at our very own Children’s Mercy Hospital. And although the journey has been a rough one with many challenges still to be faced, Granton is currently a healthy and active 5 year old. Jenni and Daniel now have three children, a daughter named Kaylynn, and a second little boy named Carver born in 2011. I noted that the Bayless family has been *twice* blessed by adult stem cell research because Carver was also born with SCID, and was treated at Children’s Mercy with an umbilical cord blood transplant as well. So far, Carver’s treatment has gone better than Granton’s, although it was recently discovered that Carver has Type I Diabetes. A number of local news reports and articles have been done on the Bayless family, but the best information on their personal journey can be found at the family’s local blogspot: <http://grantonbayless.blogspot.com/>.

Inevitably, at the end of my presentations I am approached by audience members who want to know where they can find out about these treatments. Some simply want to read more about these amazing personal stories. But there are always several people who either have family members with the same problems as the people I have talked about, or who know someone at work, in their school, church, neighborhood, etc., who could benefit from such treatments, and they want to know when this research will be available to everyone?

Sadly, that is the one question I cannot really answer.

There is a nice phrase that is used to refer to the problem of moving from clinical trials to public availability – researchers call this “clinical translation” or sometimes “translational medicine.” If one were to look back over the last ten years of published adult stem cell research, the issue of clinical translation is a constant theme. On the one hand, there is much excitement over successful trials, but they usually involved small numbers of patients and the need for larger trials is recognized. While the stories I share above are wonderful, in and of themselves they do not provide enough clinical evidence to begin sharing these treatments with everyone – rather, they represent a “proof of concept” for these procedures, and provide the impetus for further clinical study. And so, on the other hand, there is great caution about moving the research along too quickly, especially since the exact mechanisms by which various types of adult stem cells actually work in healing and regeneration are not completely understood. While the research correctly notes that there is great potential for treatments using adult stem cells, no one knows how soon they will become available.

To date, there has been very little progress in helping set up mechanisms to move adult stem cell trials safely and reliably into the clinic.

In the meantime, people continue to hear stories about successful stem cell treatments like those I mentioned above. Indeed, I offer but a small sampling of the kinds of stories one can find all over the internet. But there is an important difference in these stories. The ones that I highlight all relate to actual clinical trials which follow patients carefully in an effort to collect long-term efficacy data on the research. But an internet search will turn up all kinds of stories related to stem cell treatments, including personal testimonies of people who have gone outside the United States for therapies that are – to put it nicely – highly questionable.

I am referring to the growing problem known as “medical tourism.” One recent article sums up the problem of medical tourism as it relates to stem cell research in this way:

Much stem cell research remains at the experimental stage, with clinical trials still uncommon. However, there are over 700 clinics estimated to be operating in mostly developing countries—from Costa Rica and Argentina to China, India and Russia—that have lured many patients, mostly from industrialized countries, driven by desperation and hope, which in turn continue to fuel the growth of such tourism. (E.F. Einsiedel and H. Adamson, “Stem cell tourism and future stem cell tourists: policy and ethical implications,” *Developing World Bioethics*, April 2012, Volume 12, Number 1, pp.35-44)

There are several reasons why medical tourism is problematic, including that many of the treatments offered are unproven, conducted by doctors who are not really qualified, and provide no long-term follow-up. Many patients are “lured” to these clinics by personal testimonies of people who believe

they have been helped, playing upon the desperation of patients who are tired of waiting for these treatments to become available to them locally. Unfortunately, there have been several stories in the last few years of local people engaging in such trips for unproven stem cell treatments. In my opinion, attempting to attract vulnerable patients with unproven therapies is both unethical and dangerous.

This is where I believe **Senate Bill 199** could have a tremendous benefit, not only in the greater Kansas City area, but as providing an international model for safe, translational adult stem cell medicine. This first of its kind bill would establish a smooth process for clinical translation by facilitating the direct delivery of adult and umbilical cord blood stem cell treatments to hospitals throughout the Midwest. In addition, it would encourage the development of a network of health care professionals specifically trained in administering adult stem cell therapies. **Senate Bill 199** also includes provisions to encourage more adult stem cell clinical trials in the area, which would be of direct benefit to local citizens, and provide real hope to desperate patients and their families who might be tempted by false promises offered by unethical clinics around the globe. Finally, the bill will help encourage education to increase awareness among both practitioners and the public about the use of adult stem cells that can help separate the true hope of such research from the hype.

In close, **Senate Bill 199** is an important piece of legislation that will foster the proper clinical translation of adult stem cell research from the lab to the clinic and provide a strong response to the growing problem of unethical stem cell tourism. The State of Kansas and the University of Kansas are uniquely poised to provide an international model for the safe, responsible translation of adult stem cell research trials for future patient benefit. Given the tremendous assets and expertise available from our world-class medical university, as well as the active medical and research community in the Kansas City area, **Senate Bill 199** is both timely and necessary.

I urge you to support this effort to improve the health and well-being of all patients waiting for the promise of adult stem cell research to be fulfilled.

Thank you.

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