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Joint Kansas House and Senate Health Committees hearing

Testimony by:

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Physicians and nurses are poorly informed about available stem cell therapies. Most medical and nursing schools have no lectures about them. The medical literature and the few available CME (continuing medical education) events tend to focus on basic science rather than clinical trials or actual therapies. This means most healthcare providers are unaware of available stem cell therapies which might help their patients. In fact, the outlandish claims made in the media a few years ago during an effort to promote embryonic stem cell research has led to a backlash in the medical literature such that any talk of treatments or cures is minimized.

There are some currently available stem cell therapies which have helped individuals with certain disorders. At the same time there are some charlatans out there separating desperate people from their money by offering totally unproven "stem cell" therapies. This has led to a murky reputation for all stem cell treatments among doctors, most of whom are likely to warn their patients away from any such therapy. The general public and physicians alike would profit from an unbiased educational resource...a "consumer reports" type web site or publication, perhaps, which investigated, evaluated, and reported on such therapeutic stem cell claims. This would clear things up and inform the public about real treatments they were

previously unaware of. Perhaps consumer advocacy groups, disease specific organizations (Alzheimer's Association, Parkinson's Foundation, etc.), state and local medical societies (MD and DO), nursing organizations, medical school(s), universities, private research organizations, pharmaceutical companies, hospitals, & even the FDA could be persuaded to chip in some money to perpetually fund such an undertaking. Qualified doctors, scientists and (possibly) representatives from the funding organizations would then form a formal editorial and investigation board and publication schedule. This would be a Kansas based enterprise which would serve the whole world, and subscriptions might eventually make it a self-supporting enterprise just like "Consumer Reports."

Meanwhile, doctors and nurses could be educated about available legitimate treatment options via CME events where invited stem cell researchers and doctors from Kansas and around the world would come to Kansas to speak, such as Dr. Shinya Yamanaka recognized with the 2012 Nobel Prize for Physiology or Medicine, for his work in development of induced pluripotent stem cells (iPS cells). KU has great expertise in setting up such events. Sponsors from among those listed in the previous paragraph could help offset the cost, and physicians pay to attend. An introduction by an important political figure &/or local celebrity would increase attendance a little and get the event into the media. It would become an annual event. A spin-off would be for some volunteer doctor or scientist to repeat a summary of all this info to the public at free lectures at local libraries, etc. Since Kansas already requires it's physicians to obtain a certain number of CME hours per year, it may even be possible to require that a few of those hours be through a KU stem cell event.

Once the above items get rolling, it would be time to talk to administrators and doctors at local clinics and hospitals to get them to start offering legitimate stem cell treatments inside Kansas on such a scale that our state becomes a destination for such therapies.

Once such therapies were up and running, it would be time for a cost analysis. Depending on the numbers, the insurance companies could then be approached to start paying for the treatments, which would open them up to the masses. Kansas would become synonymous in the US with legitimate stem cell treatments and ... hope.

Starting even before the above plan, everything reasonable should be done to encourage, expand, and reward basic ethical stem cell research in Kansas. Both KU and K-State have been dabbling in the field for a while, and other research organizations like are capable of becoming involved if the right support is available.

Many neurologic diseases are thought to be good targets for stem cell research & potential therapy. Huntington's Disease, Parkinson's Disease, inborn errors of metabolism (like Pelizaeus-Merzbacher disease), MS (multiple sclerosis), ALS (Lou Gehrig's disease), and, to a lesser extent, spinal cord injury, traumatic brain injury, epilepsy, and (less promising) Alzheimer's Disease. Research into these areas will take time and money. Right now the NIH is very short of money, and by mid 2013 the state medical societies will be running short.. It would be useful to partner in some of this research with other interested parties. Traumatic brain injury and spinal cord injury would be of interest to the DOD, the NFL, and others. Parkinson's disease would be of interest to the Parkinson's Foundation, etc.

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