Midwest Stem Cell Therapy Center (MSCTC) Annual Update (30 April 2015):

Testimony of: Dana Winegarner, D.O., a general clinical neurologist at independently owned Rowe Neurology Institute in Lenexa KS, which is not affiliated with any university or hospital chain, and is not currently involved in stem cell research. He is currently the unfunded, Governor appointed Chairman of the Midwest Stem Cell Therapy Center Advisory Board.

Testimony to:

Senate Public Health and Welfare Committee Senate Ways and Means Committee House Appropriations Committee House Health and Human Services Committee State of Kansas

Testimony:

MSCTC is developing an education plan for healthcare providers and patients, and a website with a perpetually updated, interactive data base where patients and doctors can find the answer to the question, "Is there a stem cell treatment for [name the disease]," and researchers can find a clearinghouse of stem cell research information. Why bother:

- Most <u>physicians & nurses & patients lack knowledge about stem</u> <u>cell research and therapies.</u> All physicians and some nurses are taught in school what stem cells basically are, but that's where it ends. Examples:
 - a. Dr. Stephen Byer stepped far outside typical medical care when his son, Ben, had ALS. He took Ben to China for stem cell-like treatments, and later helped hundreds of people do the same, believing it would help them. The unproven procedure could have killed Ben. It didn't -- but it also didn't work. Ben later died of ALS. So did the ALS patients Byer now regrets helping get the treatment. Why take the chance? For Byer, it started with misleading promises online. "The Internet, while increasing communication, has spawned a horde of charlatans and creeps," Byer says. "We were suckered into one of the earlier forms of stem cell chicanery." (webmd.com)

- b. Twice, Dawn Gusty paid \$27,000 for stem cell treatments at a clinic in Tijuana, Mexico. Twice, her care there was completely out of step with accepted medical care for her multiple sclerosis. Twice, the procedure didn't work. Still, Gusty, of Kingston Springs, Tenn., isn't second-guessing herself. She had gone looking for something better than what her U.S. doctors could offer. (http://www.webmd.com/a-to-z-guides/features/stem-cell-treatments-false-hope-warning-signsa)
- c. My experience
- 2. Doctors do not have enough time to become more educated about stem cells on their own:
 - a. Time seeing patients: Primary Care doctors see about 3,500, and specialists about 2,700 patient visits per year, averaging 35 hours per week with those patients.
 - Paperwork: The average doctor also spends 10 hours per week doing paperwork, a large percentage of which has nothing to do with patient care (http://www.medscape.com/viewarticle/761870).
 - c. There are only about 26 doctors per 10,000 citizens in the U.S. (http://www.statista.com/statistics/186098/physicians-in-patient-care-by-age-in-the-us-since-1975/)
 - d. Already required Continuing Medical Education (CME) &
 Maintenance of Certification (MOC) courses take about 100
 hours per year for each physician.
 - e. The burden on physicians in the US results in over 400 of them committing suicide each year, which is a number thought to be growing over time.
- 3. Many websites (http://rnjournal.com/journal-of-nursing/stem-cell-research-is-our-future-of-cures) are strong advocates of only embryonic stem cell research, but many physicians and patients (https://www.aapmr.org/members/residents/newsletter/Pages/archives/Opposition-to-Human-Embryonic-Stem-Cell-Research.aspx, etc.), are opposed so there needs to be a website that is acceptable to most all doctors, nurses, and patients by being non-controversial.
- 4. Many stem cell websites are basically advertisements for their organizations or universities, rather than being an informative site.

- Many stem cell websites make false claims
 (http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm28
 6155.htm) to sucker people into spending money.
- 6. If the MSCTC website provides an interactive database accessible from the website, in addition to the ability for people to pose questions and receive answers about stem cells, it will become one of the best resources in the world.
- 7. The website will not generate income, but will raise the reputation of MSCTC to improve it's chances of getting grants, participating in studies, and enrolling patients into studies and therapies.