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Tel 913-894-1500
Fax 913-894-1502
Web www.neurokc.com

CONSULTANTS IN
NEUROLOGY, P.A.

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the practice of diagnosing and
treating neurological disorders*

8550 MARSHALL DRIVE
SUITE 100
LENEXA, KS 66214-9836

CREEKWOOD I
5400 N. OAK TRAFFICWAY
SUITE 103
KANSAS CITY, MO 64118

IMAGING CENTER
10 EAST CAMBRIDGE CIRCLE
SUITE 115
KANSAS CITY, KS 66103

*Accredited by The International
Commission for the Accreditation
of Magnetic Resonance Laboratories*

Vernon D. Rowe, MD
Diplomate, ABSM
Neurologist/Sleep Medicine

George R. Moreng, MD
Neurologist

Dana M. Winegarner, DO
Neurologist

Kenneth R. VanOwen, MD
Neurologist/Sleep Medicine

Carole Ann Guillaume, MD
Sleep Medicine

Carolyn A. Karr, PhD
Neuropsychologist

Doug Schell, ARNP, MSCN
Clinical Nurse Specialist
MS Certified Nurse

Arlene O'Shea, ARNP
Nurse Practitioner

John A. Hunter, PsyD
Institute Coordinator

Elizabeth Rowe, PhD, MBA
Senior Scientific Advisor

Rachel Williams, PhD
Research Scientist

Shane Jackson, DPT
Physical Therapist

Amy Nichols, DPT
Physical Therapist

Kelli Wong, DPT
Physical Therapist

Rose Kocour Eilts
Community Liaison

Aaron Seacat, MBA
Physician Liaison

Developing an Atmosphere of Support for Stem Cell Therapy in the State of Kansas

Kansas House Health and Human Services Committee Testimony of Dana Winegarner, DO for March 2, 2012

Sampling of diseases for which stem cell therapy has emerged or is very likely to emerge in the next few years:

Parkinson's disease:

1. Number of Kansans with Parkinson's disease: approximately 9,000.
2. Direct and indirect costs associated with Parkinson's disease for patients in Kansas: approximately \$54 million per year.
3. Clinical presentation:
 - a.
 - b.
 - c.
4. Stem cell treatment studies for Parkinson's disease: four active studies with three enrolling, but none in the United States.
5. Stem cell tourism: personal account.

ALS (Amyotrophic Lateral Sclerosis):

1. Number of Kansans with ALS: approximately 230.
2. Direct and indirect costs associated with ALS for patients in Kansas: approximately \$23 million per year.
3. Clinical presentation:
 - a.
 - b.
 - c.
4. Stem cell treatment studies: 69 studies are going on, 36 of which are enrolling, 23 of these are in the United States and none are in Kansas.

Stroke:

1. Number of Kansans with stroke: 6,400 per year.
2. Direct and indirect costs associated with stroke for patients in Kansas: \$490 million per year.
3. Clinical presentation:
 - a.
 - b.
 - c.

4. Stem cell treatment studies for stroke: there are 27 studies going on, about 19 of which are currently enrolling, eight of them being in the United States and none are in Kansas.
5. Stem cell tourism: personal account.

Multiple sclerosis:

1. Number of Kansans with multiple sclerosis: 3,600.
2. Direct and indirect costs associated with multiple sclerosis for patients in Kansas: \$36 million per year.
3. Clinical presentation:
 - a.
 - b.
 - c.
4. Stem cell treatment studies for multiple sclerosis: there are 21 studies going on, ten of which are still enrolling, three of these are in the United States and none are in Kansas.
5. Stem cell tourism: personal account.

Coronary artery disease/myocardial infarction:

1. Number of Kansans with coronary artery disease/myocardial infarction: 8,400 per year.
2. Direct and indirect costs associated with coronary artery disease/myocardial infarction for patients in Kansas: \$980 million per year.
3. Clinical presentation:
 - a.
 - b.
 - c.
4. Stem cell treatment studies for coronary artery disease/myocardial infarction: four studies are currently underway, three of which are still recruiting and none of these are in the United States.
5. Stem cell tourism: personal account.

Other diseases such as spinal muscular atrophy, corneal blindness, sepsis, type I diabetes, etc. are currently being investigated or treated with adult stem cells (please refer to www.clinicaltrials.gov).

Ins and outs of stem cell tourism:

1. No regulation of procedure, which can be different each time it is administered.
2. No regulation of quality, so sometimes patients do not know what they are actually receiving.
3. No followup regarding complications, successes, or failures.
4. No accountability for practitioners abroad (malpractice, etc.).
5. No conceivable controlled trials to verify efficacy of many offered therapies.
6. No safety reporting.

7. FBI and FDA investigations into shady stem cell clinics (in the United States).

Low-cost suggestions for helping Kansas move forward in the world of stem cell therapy:

1. Declare Stem Cell Day.
2. Website for:
 - a. Information dissemination regarding new treatments.
 - b. Information dissemination regarding/clarifying stem cell related news stories in the press.
 - c. Legal stories regarding stem cell clinics and stem cell procedures including FBI and FDA information.
 - d. Links to www.clinicaltrials.gov.
 - e. News items summarizing information from the medical literature, NIH, and other sources.
3. Bipartisan joint resolution signed by the governor requesting that CME and nursing education providers in the state incorporate education about stem cell treatments into their future courses.

Sincerely,



Dana M. Winegarner, D.O.
MIDAMERICA NEUROSCIENCE INSTITUTE
Consultants in Neurology, PC
www.neurokc.com
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