Nevada Research Consortium on Dementia (NRCD)

Inaugural Meeting Notes – Friday, November 20, 2015

Attendees:

In person: Charles Bernick (lead), Valerie Weiner, Jeffrey Cummings, Jefferson Kinney, Ronald Fiscus, Sarah Banks, Gabriel Leger, LeeAnn Mandarino

Via telephone/videoconference: Merrill Landers, Jane Fisher, Peter Reed, Jennifer Williams

Welcome: Attendees introduced themselves, their affiliations, and research interests.

Background: Senator Weiner provided a historical timeline and rationale for the creation of the Task Force on Alzheimer's Disease. The NRCD emerged as one of the recommendations of the state plan on Alzheimer's disease.

Goals of Group: Dr. Bernick discussed general goals of the NRCD and solicited suggestions from the attendees on what functions the NRCD might undertake to foster research and dissemination of information throughout the state. It was reported that the group is made up of researchers with a diverse background and just having a platform to connect researchers would be useful. Dr. Landers proposed creating panels within the group to review research grant ideas or proposals and provide a sounding board for projects. Dr. Banks suggested holding periodic meetings to share current research.

As an initial project, the idea of a website that could be a clearinghouse for researchers and research projects, along with a patient registry. Ms. Mandarino suggested having a page in the ADSD site which provides information on current research studies and how the public can participate. Also, to reach out to primary care providers to keep them in the loop so they can refer patients for clinical trials.

It was agreed that a mission statement would be a first step and could be some variation of "encourage expanded research opportunities and collaborations throughout Nevada related to Alzheimer's disease and other dementias. Disseminate emerging information within the research community, as well as to those with Alzheimer's disease, their families and caregivers." Dr. Bernick offered to refine this statement and circulate to the group via email.

Organization: The possible ways to organize the NRCD were discussed. One thought was to have some relation to the state. Senator Weiner suggested having a conversation with ADSD. Make this group a part of the TFAD family (TFAD sunsets in 2017). The status of the group and its' ability to apply for grants was also discussed and Senator Weiner suggested checking with Julie (ADSD) to see if NRCD can apply for grants as a part of a statutorily created entity housed in a subcommittee..

Methods to expand the membership of the NRCD were discussed. Dr. Fisher mentioned that UNR has an office to make contacts (e.g. to private biotech companies, etc.), and also suggested reaching out to doctoral students, include their projects on the website, and invite them to attend the meeting. Dr. Kinney mentioned that UNLV has similar resource through OSRP and endorsed the idea of getting graduate students involved.

It was suggested to create a template with each researcher's title and contact information, picture, brief bio, and research projects to place on the ADRD website. Nevada projects only (?). [See example addendum 1]

The group needs to discuss how to screen researchers who are included on the ADRD website, and to make sure they are legitimate. How do we determine this?

Action Items:

✓ 1. Create a website template for researchers and send out to group (Mandarino);
2. Create a panel of mission statement (Bernick, et al);
3. Discuss inclusion of NRCD page on the ADRC website (Mandarino);
✓ 4. Setup next meeting with presentations – video or webinar – end of January or early February (Mandarino);
5. NRCD members will each invite several potential members (all).

Addendum 1 (*Draft example of template)*

Charles Bernick, MD
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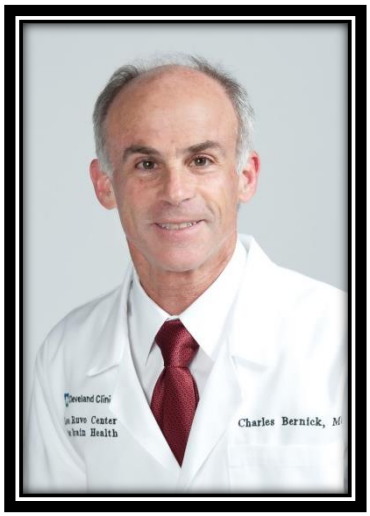

Dr. Bernick has been involved in the field of Alzheimer's disease research and treatment for over 25 years, beginning as the attending neurologist for the University of California, Davis Alzheimer's Disease Diagnostic and Treatment Center.

Dr. Bernick moved to Las Vegas in 1994 to join the University of Nevada School Of Medicine. Since that time, he has directed the development of a statewide network of Alzheimer's disease care and has been involved in various state initiatives to improve dementia care and research. In addition to co-authoring scientific articles, Dr. Bernick has participated in studies of virtually every medication now available for Alzheimer's disease.

In 2009, Dr. Bernick joined the Cleveland Clinic Lou Ruvo Center for Brain Health. He leads the Professional Fighters Brain Health study, a longitudinal cohort study of professional combatants aimed at understanding the effects of cumulative head trauma on brain structure and function.

Dr. Bernick received his MD from University of Texas Southwestern, being elected to the medical honor society, alpha omega alpha. He completed a neurology residency at the University of Miami, followed by a fellowship in neurology at the University of Arizona, and a Masters of Public Health at the University of Nevada, Las Vegas.

Dr. Bernick has served on a number of external advisory boards and committees associated with the UNLV College of Sciences, and was the founding president of the Nevada Lifespan Respite Coalition. He has been a frequent speaker at community events throughout southern Nevada.

Current Clinical Trials:

TRIALS	Therapeutic Area	Compound	Study Type	Primary Outcome Measures	Route of Admin	Study Duration	Description
A4 **Open & Actively recruiting**	Cognitively Normal	Solanezumab	Phase 3	ADCS-PACC	IV	168 Weeks	Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease (A4) Study. Tests the hypothesis that solanezumab, administered as an intravenous infusion at a dose of 400 mg every 4 weeks for 3 years, will slow cognitive decline as compared with placebo in subjects with preclinical AD.
Boxer	Tramatic Brain Injury	NA	Observa-tional	MRI	NA	156 Weeks	Designed as both a cross-sectional and longitudinal study to follow unarmed professional combatants participating in either boxing and mixed martial arts

							fighting, retired professional combatants and a matched control group that has not participated in combat sports during the study. Participants are encouraged to return annually, and are considered actively enrolled (even if they miss a yearly visit) unless they withdraw consent or are lost to follow up.
NOBLE TCAD-T817 **Closed**	Mild-Moderate AD	T-817MA	Phase 3	ADAS-Cog, ADCS-CGIC	Oral	52 Weeks	A Phase 2 multi-center, randomized, double blind, placebo-controlled, parallel group study evaluates the efficacy and safety of T-817MA in patients with mild to moderate AD Evaluates the efficacy of T-817MA as measured by ADAS-cog and ADCS-CGIC.
NOURISH **Closed**	Mild-Moderate AD	AC-1204	Phase 3	ADAS-Cog	Oral	26 weeks	A 26-week, double-blind, randomized, placebo-controlled, parallel-group study Investigates the effects of daily administration of AC-1204 in partici-pants with mild to moderate AD with an optional 26-week open-label extension. Looks at the efficacy of 26 weeks daily administration of 40 g AC-1204 (20 g caprylic triglyceride), compared with placebo in Alzheimer's Disease Assessment Scale - Cognitive Subscale (ADAS-Cog), among APOE4 participants with probable mild to moderate AD.
LZAX **Closed**	Mild-Moderate AD	Solanezumab	Phase 3	ADAS-Cog, ADCS-ADL	IV	76 weeks	Looks at the effect of passive immunization on the progression of mild AD using the study drug named solanezumab. Tests the hypothesis that solanezumab, administered as an intravenous infusion at a dose of 400 mg every 4 weeks for 76 weeks, will slow cognitive and functional decline of AD as compared with placebo in patients with mild AD.
EMERGE **Open & Actively recruiting**	Prodromal AD	Aducanumab	Clinical Trial Drug Trial	AV-45 PET	Infusion	102 Weeks	A Phase 3 multicenter, randomized, double-blind, placebo-controlled, parallel-group study. Evaluates the efficacy and safety of Aducanumab (BIIB037) in subjects with early AD Assesses the efficacy and safety of aducanumab compared with placebo in subjects with AD, including mild cognitive impairment (MCI) due to AD and a subset of mild AD. Aducanumab is a human monoclonal antibody that recognizes aggregated forms of β-amyloid (Aβ), including soluble Aβ oligomers and deposited fibrillar Aβ.