

## Nevada Consortium on Dementia Research | Friday, June 17, 2016, 12:00PM-1:00PM

Attendance: Mary Johlfs; Dr. Ronald Fiscus ; Merrill Landers; Charles Bernick; LeeAnn Mandarino; Jane Bjorklund; Isaac Santa Ana; Sandra Owens (listened in).

### Agenda:

1. NCDR website: Cheyenne from Aging and Disabilities Resource Center sent out a template 6/16/16. NCDR will have a page on the ADRC website, which will publish a comprehensive listing of Nevada research projects. Discussions included:
  - What is everyone's feeling about the website? Should we have a
    - Template with each investigator, biographical information and research projects?
    - A page devoted to the investigators and a separate research project page?
    - Links to individual organizations describing their research projects?
    - Research project software to help recruit trial participants?
  - Software system: e.g., SONA has one entry point: i.e., rather than individual organizations' research sites, have one system where researchers can enter their information, inclusion/exclusion criteria, recruiter info, etc.
    - Yearly licensing fee. About \$3000-\$5000 a year.
    - How can we fund this? Local or state agencies. Dues and fees to start? Entry fee or participation fee?
    - Goal is to have some user-friendly interface.
    - UNLV Psychology uses the SONA system.
      - ✓ Option 1: Individual
      - ✓ Option 2: Unifying system
  - Create the website initially to have links to their individual organizations' webpages, and afterward, we can create a unifying data system.
2. NCDR committee (formerly known as "the Board") to create by-laws. Four people volunteered to be on the committee:
  - i. Charles Bernick, MD  
Cleveland Clinic Lou Ruvo Center for Brain Health
  - ii. Jo Ann Pelaez-Fisher MSHA, BSN, RN  
Clinical Course Coordinator  
The College of Southern Nevada, W. Charleston Campus K206K
  - iii. Ronald R. Fiscus, Ph.D.  
*Assoc. Dean for Research, College of Medicine,  
Director, Alzheimer's, Parkinson's & Lewy Body Dementia Research Program,  
Roseman University of Health Sciences*
  - iv. Mary G. Johlfs, MS  
Director of Research Operations, Summerlin Campus (i.e. research on Neurodegenerative diseases, with special emphasis on Alzheimer's, Parkinson's and Lewy Body Dementia,). Roseman University College of Medicine.
- Start with these Committee Volunteers and schedule a time to meet to create by-laws. Find a similar organization and modify and cater to our consortium. Use a template.

3. In the next meeting, would like a member to present themselves and their research for approximately 15 minutes. Dr. Fiscus volunteered to do this.
4. Next meeting will be face-to-face at the Lou Ruvo Center and we will video-conference with Northern Nevada.
  - a. **Early September, first Friday, September 2, 12 – 1:30 PM?**

**Action Items:**

1. Committee will begin creating by-laws for the NCDR.
2. Dr. Fiscus will prepare for September presentation
3. NCDR members will send in biosketches and research projects to LeeAnn Mandarino [mandarl@ccf.org](mailto:mandarl@ccf.org) or Isaac Santa Ana [santai@ccf.org](mailto:santai@ccf.org).
4. Cheyenne Pasquale will continue to work on the NCDR website.