

Fellow ALSRG Members,

I am very excited about all the new projects we are starting together! Below there is a summary of the projects discussed at this morning's meeting, along with a list of the project leader (L) and other project committee members. I will check in with each leader in a month or so to see how things are coming along. If there are any others of you who want to help with one or more of these, please let me or the individual project leaders know who you are.

In the meantime, as relates to our ALSUntangled project, please go to [www.twitter.com](http://www.twitter.com) and sign up for an account. Then sign on to follow ALSUntangled. That way you will get all of our tweets. Also, look for a second email soon from our NING which is your invitation to join that part. Simply click on the "accept invitation" link in the email, and it will ask you to create a username and password, and you are in. See you in there!  
Rick

ALSRG Projects As Of 12/8/09

1. Post AAN ALS Practice Guideline Slides for the ALSRG Website that members can use when they speak to patient groups and other neurologists: Bob Miller will email slides to Rick Bedlack for posting.
2. Propose promising "home-based outcome measures" for validation in future consortia trials: Michael Benatar (L), Ed Karsarskis.
3. Create an "Army of PALS" online potential research subject listing, similar to the "Army of Women": Alex Sherman (L), Nazem Atassi.
4. Develop an ALS Clinical Research Learning Institute, similar to the Parkinson's Clinical Research Learning Institute, which trains patients to be effective research advocates: Rick Bedlack (L), Nazem Atassi, Terri Heiman-Patterson, Merit Cudkowicz, Lucie Bruijn.
5. Participate in ALSUntangled: Rick Bedlack (L), All ALSRG Members!
6. Attend National ALS Advocacy Days May 9-11 in Washington DC: All ALSRG Members!
7. Build an ALS Patient Safety Organization: Ben Brooks (L), Steve Ringel, Bob Miller
8. Create a National ALS Tissue Bank: Needs a leader and committee members.
9. Update ALSRG Website: Eric Sorenson (L)