PERC Large Group Meeting 10/13/14

1. AES Meeting: Monday morning 7AM-8:30AM
   1. Best time, this does conflict with keto hour
2. Still accepting nominations for the steering committee to be voted on in AES
   1. You may nominate yourself
3. CNDC (Colorado Nonprofit Development Center)
   1. We were accepted as a nonprofit group and will be able to accept donations in the next 1-2 weeks
   2. Bylaws and membership agreements are being reviewed by their lawyers to ensure we are protected
   3. We have developed a budget but we will need to designate a financial officer
4. Database
   1. You may be receiving clarification emails – thank you for replying quickly!
   2. New quality control measures are being implemented
5. Infantile spasms
   1. Standardized protocol has been in place for several years
   2. Infantile spasms group will restart meetings to discuss next steps
   3. Randomized trial?
      1. Funding – some possibilities but we will need to put together a solid research plan
      2. Thoughts are randomization without blinding
         1. COPE study – randomized to LMT, OXC, or LVT without blinding
            1. It is based on a randomization program with several variables
         2. Oncology group has a long history of this – they have definitive outcome measures, we have EEG
      3. There is definite interest amongst centers in participating in this trial
   4. Should we be altering the “standard of care” based on the data so far?
      1. Oncology model would be to change “standard of care”, have 50% of providers continue with prior plan and 50% adopt change
   5. Trisomy 21 group – there are no updates as of now in regards to funding availability for this group
6. Rare disease
   1. Standard of care development
   2. Oncology has working groups for each disease to define protocols
   3. Epilepsy Genetic Initiative through CURE (5 sites) – exomes will be shared with central database with some phenotypic information and exomes will be rerun to try to identify new genes
      1. As the goal of this project is not clinical right now, should not overlap
      2. Are those sites part of our consortium – yes, at least the US sites
      3. Patient do not qualify for this if they have a known diagnosis not found on exome
      4. CURE is interested in expanding this project but that is not how the protocol is currently written
      5. We should work with CURE to incorporate that data into our working groups, that may even be a source of funding
   4. Characteristic diseases/etiologies that would be reasonable to target (suggestions)
      1. **Infantile spasms** - *exists*
      2. **Dravet Syndrome** - *exists*
      3. **Myoclonic Atonic Epilepsy**
      4. LGS
      5. Epilepsy with myoclonic absences
      6. KCNQ2 - *exists*
      7. Ohtahara/EME - *planned*
      8. Malignant migrating focal epilepsy
      9. Focal cortical dysplasia
      10. “Epilepsy of unknown cause under age 1” – too broad?
   5. Plan to discuss more at AES, develop focus groups – thoughts are to pick a few to start and then move on from there (highlighted were suggested at the meeting)
7. Next meeting – AES, then we will have a phone conference in February