PERC AES meeting 12-8-14

1. 2014 accomplishments

* 4 posters and 4 papers in progress based on NISC data, one near submission
* Amended guidelines to standard of care for IS
* Nonprofit status through CNDC
* Trial for IS formally being planned
* Grown in centers, 38

2. Abstracts

* See attachment with abstract details
* Characteristics of other seizure types associated with infantile spasms
* Comments: Was there a delay based on medication choice?
* Time elapsed from onset of infantile spasms to diagnosis and treatment
* Comment: In the future can we capture whether there was a pediatrician or parental delay in recognition of spasms?
* \*\*Can we improve standardization of DOCUMENTATION between centers, not just treatment
* Etiologies and yield of investigations of infantile spasms
* Comments: Can we pursue a survey of state to state provider impression of barriers to ordering genetic testing?
* Data shows metabolic testing is low yield – can that be translated into recommendations for earlier genetic testing, rather than metabolic?
* Moving towards standardization of care and improved treatment
* Comments: Why is our ACTH effectiveness rate lower than previously reported – more stringent remission criteria, wider sample of centers, observational nature of study

3. Website

* Has been rebuilt at same web address – pediatricerc.com – still under construction!
* Can we convert this to .org?
* Please send comments/suggestions to Kelly

4. Nonprofit status – CNDC (Colorado Nonprofit Development Center)

* There will be a paypal donation page linked to our website
* We can receive unrestricted grants through this link or by direct contact with CNDC
* CNDC charges $450 annually at significant benefit to us – legal and administrative support, HR resources
* Should we start asking for a minimal membership fee to cover this cost – $15-25 per institution? – For now, please consider a small donation!
* Financial goals for next year
* Create a more detailed budget
* Hire a staff assistant

5. Bylaws

* Amended version was distributed by email (and attached to this email)
* Clarified that PERC facilitates collaboration and does not coordinate research itself – this is important to minimize risk
* Clarification points:
* Who is the member, the individual or institution?
* Should we expand steering committee to include an attorney or a community representative
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6. Steering committee

* Anne Berg is rotating off this year
* Two new nominees – Renee Shellhaas and Charuta Joshi
* Ballot collected at the end of the meeting – results to be announced!
* Steering committee goals for the upcoming year:
* Finalization of bylaws
* Budget development/financial plan
* Donor identification

7. Future endeavors

* Development of small working groups to improve standard of care – PLEASE EMAIL CONTACT IF YOU ARE INTERESTED IN MOVING ONE OF THESE PROPOSALS FORWARD
* Start by working on small group of individual syndromes and expand with time
* Proposals:
* Dravet – already in progress, Delphi process for expert input, lit review ongoing
* Funded by Dravet Foundation
* Contact: Elaine Wirrell
* LGS – there is funding available
* Contact: Mary Zupanc
* Nonsyndromic new onset epilepsy – standardize initial medication choices (4 most common in EOEC) and dosing strategy
* Contact: Renee Shellhaas/Bill Gaillard
* Ohtahara (or severe early life epilepsies)
* Contact: John Millichap
* Examining impact of multidisciplinary centers on quality of care/cost effectiveness
* Starting with survey of centers to determine current practice/resources
* We need to start including other health professionals in PERC – ie neuropsychologists, etc
* Contact: Lori Hamikwa
* PLEASE EMAIL STEERING COMMITTEE IF YOU HAVE INTEREST IN STARTING AN ADDITIONAL GROUP

7. Projects to be aware of:

* Epilepsy Genetics Initiative (EGI)
* Funded by CURE
* Attempting to collect WES raw trio data from genetic testing companies with patient consent to better identify pathogenic variants
* Clinical results – if variant found, will be sent back to company for confirmation and then released for clinical use
* National Coordinating Center for Children and Youth with Epilepsy
* AAP has grant from government
* Mission is to improve access to care in underserved areas
* Educational initiatives, QI measures, rural health component
* Advisory committee – CURE, CNS, etc.
* Visiting professorships for neurology/epilepsy.
* Must be AAP member, section of neurology.
* Sucheta Joshi will be the liaison