Supporting CDKL5

Catastrophic Childhood Epilepsy: A Recent Convergence of Basic and Clinical Science.
www.ScienceTranslationalmedicine.org   2014.

This is an excellent review of what are termed the "Catastrophic" epilepsies, their causes and the development of future research and therapeutic strategies. The paper is not about CDKL5, but we are in there somewhere. The authors make suggestions about recommendations and proposed future directions.

1: Create new experimental models to understand seizure mechanisms and develop therapies
2: Apply new technologies for probing distributed neuronal networks
3: Use a top-down approach
4: Test currently approved drugs for other clinical indications
5: Engage pharma and the biotech industries
6: Expand resource sharing
7: Create data warehouses

I think points 6 and 7 are particularly relevant as they refer to the "sharing" of research resources such as animal models and other tools such as iPS cells, so that any interested research group could utilize resources that have already been developed. They also advocate the development of "data warehouses" which would include common data elements so that individuals from different institutions could add to the database. Patient data would then be widely available to researchers and clinicians – now there's an idea!!!

Note – The point I personally take away from this is that CDKL5 is but a very small fish in a small pond in a very big world. If we don't all stick together and pool our resources both in terms of supporting research and the development of therapeutic strategies then we may be inadvertently shooting ourselves (or perhaps our children) in the proverbial foot. I don't personally believe that there is any place for academic or any other territorial self-interests which ultimately can only hinder the important and necessary work that needs to be done in order to progress the understanding of CDKL5 and hopefully the development of future therapies.