**TSC Alliance**

**Government Relations Strategy Meeting Notes**

**September 19, 2024**

In attendance:

Government Relations Committee Members: Chip Burkhalter (Chair), Julie Blum, Sara Chieffo, Ted Mastroianni, John Richards, Andrew Sperling

Guests: Kristin Burkhalter, Mark Vieth

Staff: Kari Rosbeck, Katie Smith

Background information for environment scan: The [Epilepsy Action Network](https://www.epilepsiesactionnetwork.org/thenationalplan) (EAN)– Is working on legislation that would create a National Plan for Epilepsy. The National Plan legislation authorizes different government agencies to work together. These have been created for autism, Alzheimer‘s Disease, ALS and Parkinsons. The TSC Alliance is a member of EAN and Kari sits on their advisory board. Senators Amy Klobuchar (D-MN) and Eric Schmitt (R-MO) are chairing the Senate Epilepsy Caucus.

Global Genes is working on a campaign for rare disease similar to Stand Up for Cancer or work the Komen Foundation has done. It’s confidential at this time and in the very early stages and may be beneficial for raising awareness in the future. Kari also serves on the advisory board for the campaign.

**TSCRP Funding**

What can we do to increase this funding, especially now with Senator Schmitt in office? The CDMRP has been flat funded at around 1.5 billion since FY19.

What are the obstacles for getting an increase? Could we go for $20 million? Could the Senate have a line item for the TSCRP?

* Would need a Senator going to advocate to the Committee Chair for funding
* Member to member conversations, ex. Having Senators Schmitt and Mullin talk to their colleagues, either individually or as a team. The House and Senate approaches should be viewed as two separate things, with the Seante taking place behind the scenes.
* In the larger context of funding – where does this fit? How can we make the best case in asking for $20 million when there will be other budgetary concerns?
* What bigger case do we make for this – if we had 10 million more what we do with it? Clinical trials, especially investigator initiated clinical trials; growing the clinical research consortium, QI initiatives; would TAND or mental health be a way to approach and leverage funds – start thinking more about what could be done vs. what is being done
* What are some of the common funding mechanisms in the CDMRP? Prostate cancer may have a different mechanism than other CDMRPs.
* Also think about making the case for how funding impacts can impact a state.

**Action:** Talk to Drew Dziedzic in Senator Schmitt’s office; Ted had a good meeting with Rep. Cole’s office – might be worthwhile to contact him

**Next steps**

Phase 1-

* Put together a compelling list on what a big jump in funding would do. Talk to Steve Roberds, Peter Crino, Elizabeth Thiele, Shafali Jeste, Mustafa Sahin.
* Who do we need to talk to in phase 1 – letter leads and Schmitt and Mullin

Phase 2 –

* Power map how our ask can help with something with a member of congress is already interested
* Consider doing more with committee members to get buy in, especially to increase Republican support. There may be resistance to increasing program funding due to optics of which programs get additional funding.

**Action:** Is there a way to have a TSCPR lunch among the Republican Senators that could be initiated by Senators Schmitt and Mullin? Could they invite Kari plus guest to lunch in the Senate dining room and see who else they would like to invite?

**Action:** Put together a campaign plan for what we want to do and when we want to do it to get to 20 million, ex. here’s the context, here are our goals, etc.

**Action:** Ask Amy Klimas how to get a consumer reviewer on the programmatic panel for the TSCRP and think strategically about who to add.

**State funding**

MD – Dr. Crino and the University of Maryland recommend not doing anything to draw attention to the UMD funding.

**Action:** Kari and Katie to get in contact with Frederica Struse; thank Senator Feldman at possibly at Maryland Walk 2025.

Other states to consider: IL – Stephanie McCann’s college roommate is a state senator; WA; PA.

**Other things**

Meeting with CDC after TSC Alliance staff meet with NIHCD on newborn screening this winter.

Met with Angelman’s Syndrome, ARC and Annie Kennedy to develop plan on advocating for improvement in transition services and waivers and Medicaid coverage. Once plan is in place, reach out to Colin Ferrel’s foundation about Hill event.