Tennessee Rare Disease Advisory Committee (RDAC)

Our mission is to improve the quality of life of individuals affected by rare diseases in Tennessee through collaboration, education, support and advocacy.

Agenda November 30, 2022

RDAC Members In attendance: Scott Strome, Gillian Hooker, Kim Stephens, Rizwan Hamid, Tracey Lovett, Reginald French, Chip Chambers, Richard Finkel

Others in attendance: Ally Ladd, Kerry Engebrecht, Erin Frey, David Connor, Rachelle Dixon, Todd Barber

Agenda Item	*Notes*	*Action items*
Call to order and Welcome	Gillian Hooker, Secretary Treasurer, TN RDAC	
Rare Disease Story	Allie Sublett Ladd, Kennedy Ladd Foundation Has 2 children with MPS1 Hurler Syndrome Her daughter was diagnosed first when she was a baby, first asked questions at 3 months, then 6 months. Her daughter was diagnosed at 10 months of age, given prognosis of 5-10 years of life. At the time, treatment options were really limited. Drove weekly to Cincinnati Children's for enzyme therapy then moved to bone marrow transplant. They are thankful to have Commercial insurance, which allows them to travel to a Center of Excellence. Her first transplant failed, then had a second at 12 months. She is now 8 years old Cord blood was a factor in both of her kids treatment. Kennedy's biggest ongoing challenges are bone issues and spine issues. She has spinal surgeries, hip and knee surgeries planned in the next year.	

	Her son Lincoln was diagnosed as a newborn. He doesn't have many of the other features that his sister has - the early diagnosis was very beneficial in their family. TN now has MPS1 on NBS - He started ERT at 3 months. Then had a transplant at 4 mos of age. He had a shorter hospital stay - he is currently 4 years post- transplant. Their points of advocacy: - Cure - Early Dx - Access to centers of excellence Created the Kennedy Ladd Foundation - Also cited the Katie Beckett program in TN - very grateful for that. Katie Beckett - provided wheelchair and a medical stroller - Story highlights the benefits of both early diagnosis and having good insurance. E.g. being able to go to centers of excellence. Also discussed what the policies would be that provide access to Centers of excellence- both federal and state policies are needed. Also heard from Kerri Engegrecht - community ambassador to the Rare Action Network. David Connor - Rare Disease Data Trust - solution to accelerate discovery and diagnosis for rare disease patients. Presented their solutions -	
TN Expanded Genomic Diagnostics Program update / TN Rare and Undiagnosed Disease Network	Rizwan Hamid, RDAC Member Scott Strome, RDAC Chair Chip Chambers, RDAC Member Terry Jo Bichell, RDAC Vice-chair Working on plan to meet with Dr. Wu, putting together the materials and agenda for the meeting.	Schedule meeting with TennCare CMO, Dr. Victor Wu

Update on Pilot Project & Next steps	We are hoping to create a model that could help other states as well.	
RDAC Members Finishing Terms / Succession Planning	Terry Jo Bichell, RDAC Vice chair Discussed transition of TennCare representation from Lora Underwood to Tracey Lovett	Communicate with governor's office about transition from Lora Underwood to Tracey Lovett Schedule call w/ leadership to talk about open positions and succession planning.
Brief Updates Pharmacy Advisory Committee Update (see circulated notes) DUR Update Department of Intellectual and Developmental Disabilities	Reginald French, RDAC Member Tracey Lovett, RDAC Member Lora Underwood, Have not had a DUR meeting yet in 2022 - there will be meetings coming up in 2023 - L. Underwood will circulate the dates for 2023. Terry Jo Bichell, RDAC Vice Chair	
Review of Action Items and Agenda Items for December Meeting	Scott Strome, RDAC Chair	