

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 January 26th, 2022

8:00-8:05 CT	Call to order and Welcome	Scott Strome, RDAC Chair
8:05-8:30 CT	Patient Story	Linda Pilkinton, Bright Heart Foundation
8:30-8:50 CT	TN Expanded Genomic Diagnostics Program update / TN Rare and Undiagnosed Disease Network <i>Update</i>	Rizwan Hamid, RDAC Member Scott Strome, RDAC Chair Chip Chambers, RDAC Member Terry Jo Bichell, RDAC Vice-chair
8:50-9:15	2022 Planning <ul style="list-style-type: none"> - In person meetings? - New Appointments - New Initiatives - TennCare needs 	Scott Strome, RDAC Chair
9:15-9:30	Brief Updates Term Limits / Succession Pharmacy Advisory Committee Update DUR Update Newborn Screening / Genetics Advisory Committee Updates Department of Intellectual and Developmental Disabilities Rare Disease Virtual Hill Day Upcoming https://everylifefoundation.org/rare-advocates/rare-disease-week/	Terry Jo Bichell, RDAC Members Reginald French, RDAC Member Lora Underwood, RDAC Member Megan Crow, RDAC Member - <i>Notes circulated with agenda</i> Rizwan Hamid, RDAC Member Terry Jo Bichell, RDAC Vice Chair Kim Stephens, RDAC Member
Closing	Review of Action Items and Agenda Items for December Meeting	Scott Strome, RDAC Chair