

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 October 27th, 2021

8:00-8:05 CT	Call to order and Welcome	Scott Strome, RDAC Chair
8:05-8:25	Rare Disease Patient Perspective	Kim Stephens, RDAC Member
8:25-8:55	Emerging Therapies in Rare Disease	Marshall Summar, MD
8:55-9:00	Annual Report Development <i>Update</i>	Terry Jo Bichell, RDAC Vice-chair Gillian Hooker, RDAC Member
9:00-9:15	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
9:15-9:20	Upcoming Meeting Schedule	Gillian Hooker, RDAC Member
9:20-9:30	Brief Updates Term Limits / Succession Pharmacy Advisory Committee Update DUR Update Newborn Screening / Genetics Advisory Committee Updates Department of Intellectual and Developmental Disabilities TN Rare Disease Survey	Terry Jo Bichell, RDAC Members Reginald French, RDAC Member Lora Underwood, RDAC Member Megan Crow, RDAC Member 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