

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 August 25th, 2021

8:00-8:05 CT	Call to order and Welcome	Scott Strome, RDAC Chair
8:05-8:30	Rare Disease Patient Perspective	Alexis Gordon
8:30-8:35	Sunset Hearing w/ TN Comptroller	Gillian Hooker, RDAC Member Terry Jo Bichell, RDAC member
8:35-8:40	Annual Report Development	Gillian Hooker, RDAC Member Terry Jo Bichell, RDAC member
8:40-8:50	TN Expanded Genomic Diagnostics Program update / TN Rare and Undiagnosed Disease Network	Rizwan Hamid, RDAC Member Scott Strome, RDAC Member Terry Jo Bichell, RDAC Member
8:50-9:00	TennCare Legislative Update - S.B. 1617	Ashley Reed, TennCare
9:00-9:05	Pharmacy Advisory Committee Update & Planning for upcoming meeting	Reginald French, RDAC Member Lora Underwood, RDAC Member
9:10-9:15	DUR Update	Megan Crow, RDAC Member
9:15-9:20	Newborn Screening / Genetics Advisory Committee Updates	Rizwan Hamid, RDAC Member
9:20-9:25	Department of Intellectual and Developmental Disabilities	Terry Jo Bichell, RDAC Vice Chair
9:25-9:30	Survey Update	Kim Stephens, RDAC Member
Closing	Review of Action Items and Agenda Items for December Meeting	Scott Strome, Chair, TN RDAC