

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 22nd, 2025

8:00-8:05 CT	Call to order and Welcome	Gillian W. Hooker, Interim RDAC Chair
8:05-8:25	Patient Story	Jess Wild, KDM5C parent
8:25-8:45	Project FIND-OUT Update	COMBINED Brain Elizabeth Rountree, Combined Brain Terry Jo Bichell, RDAC Vice Chair
8:45-9:00	Medical Foods	Lametra Scott, RDAC Member
9:00-9:15	Rare Disease Day 2025	Gillian W. Hooker, Interim RDAC Chair Terry Jo Bichell, RDAC Vice Chair
9:15-9:20	Pharmacy Advisory Committee Update DUR Update Department of Intellectual and Developmental Disabilities Newborn Screening	Reginald French, RDAC Member Tracey Lovett, RDAC Member Terry Jo Bichell, RDAC Vice Chair Rizwan Hamid, RDAC Interim Secretary
9:20-9:30 Closing	Review of Action Items and Agenda Items for March Meeting (3/26/25)	Gillian Hooker, RDAC Interim Chair