

## 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 May 22nd, 2024

<b>8:00-8:05 CT</b>	Call to order and Welcome	Gillian W. Hooker, Interim RDAC Chair
<b>8:05-8:25</b>	Patient Story	Danielle Jones, KBG syndrome parent
<b>8:25-8:45</b>	Update: Rare Disease Legislation <ul style="list-style-type: none"> <li>● WGS bill</li> <li>● NBS bill</li> <li>● CMMI Sickle Cell project</li> </ul>	Gillian W. Hooker, Interim RDAC Chair Terry Jo Bichell, RDAC Vice Chair
<b>8:45-9:00</b>	RDAC Recommendations Protocol	Gillian W. Hooker, Interim RDAC Chair Terry Jo Bichell, RDAC Vice Chair
<b>9:00-9:10</b>	Pharmacy Advisory Committee Update	Reginald French, RDAC Member
	DUR Update	Tracey Lovett, RDAC Member
	Department of Intellectual and Developmental Disabilities	Terry Jo Bichell, RDAC Vice Chair
	Newborn Screening	Rizwan Hamid, RDAC Interim Secretary
<b>9:10-9:15 Closing</b>	Review of Action Items and Agenda Items for July Meeting	Gillian Hooker, RDAC Interim Chair