

## 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 23, 2023

<b>8:00-8:05 CT</b>	Call to order and Welcome	Scott Strome, RDAC Chair
<b>8:05-8:20</b>	Update on TN Diagnostics Network Project	Ashley McMinn, Project Manager Rizwan Hamid, RDAC Member
<b>8:20-8:35</b>	Rett syndrome & the first and only FDA-approved treatment for Rett syndrome	Kemi Olabisi PharmD, BCPS Holly Murphy Acadia Pharmaceuticals Inc  Jaimie Patrick International Rett Syndrome Foundation TN Family Empowerment Team
<b>8:35-8:50</b>	Updates on Skyclarys for Friedrich's Ataxia	Robert Jaramillo Alex Tabraue Reata Pharmaceuticals
<b>8:50-9:00</b>	RDAC Succession Planning	Terry Jo Bichell, RDAC Vice-Chair
<b>9:00-9:25</b>	Patient Story	Diamond Shriner, Parent to Quinnlee Mae Shriner
	Brief Updates to circulated by email  Pharmacy Advisory Committee Update (see circulated notes)  DUR Update  Department of Intellectual and Developmental Disabilities	Reginald French, RDAC Member  Tracey Lovett, RDAC Member  Terry Jo Bichell, RDAC Vice Chair
<b>Closing</b>	Review of Action Items and Agenda Items for December Meeting	Scott Strome, RDAC Chair