

## 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.*

Minutes September 22nd, 2021

RDAC Members in Attendance: Scott Strome (Chair) Terry Jo Bichell (Vice Chair) Gillian Hooker (Secretary) Kim Stephens, Megan Crow, Clay Callison, Chip Chambers, Lora Underwood, Rizwan Hamid,

Other Attendees: Todd Barber, Ashley McMinn, Jackie Menzel

Call to order and Welcome	Scott Strome, RDAC Chair	Thank you to Bichell, Hooker, Hamid for Sunrise Hearing
Rare Disease Patient Perspective	<p>Shannon Miller</p> <p>41yo from Knoxville, has Cystic Fibrosis, dx at 5 mos old via sweat test, failure to thrive. Not much lung involvement as a baby. Life expectancy when she was diagnosed was 10yo.</p> <p>She was hospitalized frequently in her teens, and experienced a significant drop in lung function in 2005 and stopped working at that point.</p> <p>She currently has Medicare and Tricare insurance.</p> <p>She is taking the new channel modulator, Tricafra, from Vertex, which is covered by insurance, but has an incredibly high copay. Her specialty vitamins (\$250/month) are not covered by Medicare.</p> <p>Before Tricafra, needed iv abx every 4-6 months, has needed them twice in 2 years, so has lengthened time between exacerbations.</p> <p>The group had a discussion about supplements for patients with rare disease and also the extent to which this is a national issue, a MAC issue or a state issue.</p>	<p>Draft a memo to outline instances in which supplements are critical for individuals with rare diseases</p> <p>Lora will help the committee to develop a covered/not covered status for drugs on the list</p> <p>Agenda for next time</p>
Sunset Hearing w/ TN Comptroller Follow Up	<p>Gillian Hooker, RDAC Member</p> <p>Provided update to the committee that the RDAC has been renewed for 6 years. State legislators were very engaged and pleased with the progress made by the RDAC.</p>	Update website with news of RDAC renewal

<b>Term Limits / Succession Planning</b>	<p>Gillian Hooker, RDAC Member Term limits 1, 2, 3 year terms, intentionally staggered.</p> <p>We can request to renew our terms.</p> <p>Voted unanimously to recommend to the governor that Scott Strome continue as chair</p> <p>Also discussed that if a member decides to roll off, we could consider replacing that member with someone from an underrepresented area of the state</p> <p>Lora recommended that we appoint a point person to stay on top of the appointments, keeping records of appointments.</p>	<p>Terry Jo Bichell &amp; Gillian Hooker will follow up with all other RDAC members with expiring appointments to make sure reappointment and/or new appointment paperwork is submitted</p> <p>Lora Underwood will provide contact information for state regulators who should be involved.</p> <p>May consider adding a new member.</p>
<b>Annual Report Development Update</b>	Terry Jo Bichell, RDAC member	Continuing to work on the outline.
<b>Survey Update</b>	<p>Kim Stephens, RDAC Member</p> <p>87 survey respondents</p> <p>Continue to think about ways to both broaden the recruitment efforts and also efforts to publish the survey.</p>	Consider a new flyer/email for circulation
<b>TN Expanded Genomic Diagnostics Program update / TN Rare and Undiagnosed Disease Network Update</b>	<p>Rizwan Hamid, RDAC Member Scott Strome, RDAC Member Chip Chambers, RDAC Member</p> <p>Continuing to meet.</p> <p>Program managers have been identified, on at UT and one a VUMC.</p>	Group will continue to meet.
<b>Liaison Updates</b>  <b>PAC</b>  <b>DUR</b>  <b>Newborn Screening</b>  <b>Intellectual and Developmental Disabilities</b>	<p>Reginald French, RDAC Member - Lora Underwood, RDAC Member</p> <p>No PAC update - next meeting in November. Lora is pregnant, will not be at Dec and Jan meetings</p> <p>Megan Crow, RDAC Member - Next DUR Meeting is Oct 12</p> <p>Rizwan Hamid, RDAC Member - Next Newborn Screening meeting is Nov</p> <p>Terry Jo Bichell, RDAC Vice Chair - Appointed to the statewide DIDD committee. She will continue to provide updates.</p>	