

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.

RDAC Members in Attendance: Scott Strome, Terry Jo Bichell, Kim Stephens, Chip Chambers, Megan Crow, Lora Underwood, Reginald French, Suzanne Jakowski

Other Attendees: Abby Trotter, Todd Barber, Molly Devitt, Lucy Shell, Shelley Courington

Agenda March 24th, 2021

<i>Agenda Item</i>	<i>Presenter</i>	<i>Notes</i>
Call to order and Welcome	Scott Strome, Chair, TN RDAC	
Rare Disease Patient Story	Molly Devitt, Parent	<p>President of the TN PKU foundation, worked with the national alliance as well. Legislation and advocacy agenda - in TN and in DC.</p> <p>Rep Blackburn as a cosponsor of their house bill - Medical Nutrition Equity Act. They plan to seek her support in the senate as well. One hang up has been scope - and how to define prescription diets. They got a CBO score for the costs.</p> <p>Molly is a dietician, and was well-equipped to manage the PKU diet when her daughter was diagnosed.</p> <p>Her insurance covers her medical foods and formulas, which are essential for her. She needs a special formula 3x a day that costs \$15/day.</p> <p>People in TN are still struggling - people without insurance, or moms who are pregnant with PKU</p> <p>TennCare provides \$400/month for kids, which barely covers formula and people age out of coverage at 18.</p> <p>In TN, with pos NBS, they are immediately referred.</p> <p>They have a home delivery PKU pantry - and a grant to support people in need of additional assistance, and those who do not have insurance.</p> <p>There is a higher prevalence of eating disorders in</p>

		<p>the PKU population - living on the regimented diet can lead to obsessive eating and/or emotional challenges related to eating.</p> <p>Job changes can be a challenge for those who need to maintain coverage for medical foods and fear changing insurance plans. NORD also helps to cover foods.</p> <p>There is one medication called CUVAN for some people with PKU.</p>
<p>TN Rare Disease Survey Update</p>	<p>Kim Stephens, RDAC Member</p>	<p>Survey is ready to go, will be sent with the press release.</p> <p>Action Item: All RDAC members to share link to survey once it's ready with all members of the rare disease community.</p>
<p>TN Legislative Agenda Updates</p> <p>SB1397/HB 619 Copay accumulator reform</p> <p>SB1617/HB1398 PBM Reform Bill</p> <p>SB1310HB0677 Step Therapy Bill</p> <p>Federal Medicaid Expansion</p>	<p>Megan Crow, RDAC Member</p> <p>Lucy Adkins, TN Pharmacy Association</p> <p>Shelley Courington, Patient Access Choice Transparency</p> <p>Megan Crow, Terry Jo Bichell, RDAC Members</p> <p>Terry Jo Bichell</p>	<p>Copay accumulators: Megan gave an update on the copay accumulator bill - Insurance companies and PBM have but these accumulators in place to stop 3rd party assistance from counting towards a deductible. Megan uses copay assistance to afford her child's copays for hemophilia and this support is critical.</p> <p>Insurance companies worry that the manufacturers coupons pervert incentives to use lower cost drugs.</p> <p>The bill would ask all money to count toward deductible - So far, it has received positive recommendations and no negative recommendations.</p> <p>This is only for private insurance, Medicare and medicaid do not allow this.</p> <p>PBM Reform Bill:</p> <p>Came out of committee in senate moving to house side next week. As introduced, makes certain changes regarding pharmacy benefits and pharmacy benefits managers. - Amends TCA Title 4; Title 56 and Title 71.</p> <p>Bill Summary: https://wapp.capitol.tn.gov/apps/BillInfo/Default.aspx?BillNumber=SB1617</p> <p>There is a coalition supporting this bill - PACT (Patient Access Choice Transparency)- patients for access control and advocacy doing the constituent story to be shared with legislators. Shelley "switching pharmacies can be a nightmare for</p>

		<p>patients. This bill addresses a lot of aspects that give patients the ability to be back in the center of these decisions. Now insurers and PBMs are in control, and this legislation is patient-centered. This is a patient-centered piece of legislation.”</p> <p>PACT will provide a written summary It is posted to the slack channel.</p> <p>TNCare may have concerns about the cost of the bill.</p> <p>Step Therapy Bill All of the group expressed support for this bill.</p> <p>Actions from committee: Abby will reach out for more background information on the above bills and any opposition to the bills.</p> <p>Subcommittee will convene in the next week to determine what the communication from the RDAC will be to TennCare and State Legislators. Options include an open letter, or official support of one or more of the bills.</p>
Logo Approval	Megan Crow, RDAC Member	Logo Approved for use on the website
Website Update	Todd Barber, UT Abby Trotter, Liaison LifeScience TN Megan Crow, RDAC Member Reginald French , RDAC Member Gillian Hooker, RDAC Member Terry Jo Bichell, RDAC Member Kim Stephens, RDAC Member	Deferred to Next Meeting
Review TN RDAC Press Release Plan	Abby Trotter, Liaison LifeScience TN	<p>Just a few days away from getting the press release out.</p> <p>Action Item: All committee members will share press release on social media and with relevant channels.</p>
Liaison Updates <ol style="list-style-type: none"> 1. Pharmacy Advisory Committee 2. Drug Utilization Review Committee 3. Newborn Screening 4. Department of Intellectual 	Reginald French, RDAC Member Megan Crow, RDAC Member Rizwan Hamid, RDAC Member Terry Jo Bichell, RDAC	Deferred to Next Meeting

and Developmental Disabilities	Member	
Review of Action Items and Agenda Items for December Meeting	Scott Strome, Chair, TN RDAC	