

## TennCare 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 (January 27th, 2020)

	Notes	Action Items
<b>Call to order and Welcome</b>	<b>Scott Strome, Chair, TN RDAC</b>	
<b>Rare Disease Patient Story</b>	<b>Janet Patterson, parent, carrier of rare disease</b>	
<b>Discussion of Vision Statement, RDAC Goals</b>	<p><b>Scott Strome, Chair, TN RDAC</b></p> <p>Question of Vision - willingness to support development and implementation of new drugs</p> <p>Important function is committee reports-liaison groups</p> <p>Review different policies and drugs considered by TennCare</p> <p>Survey forthcoming</p>	
<b>TN Rare Disease Survey Update</b>	<p><b>Kim Stephens</b></p> <p>Modeled on the PA RDAC, survey Monkey, Western IRB</p> <p>Has been shared on slack</p> <p>Plan to deploy survey during rare disease week</p> <p>Fees - we have no budget. Survey monkey \$225, Use UT platform</p> <p>\$1200 IRB approval - free through UT</p>	<p><b>All</b> - provide feedback Survey link: <a href="https://forms.gle/aXs2v8wrWhNt667g8">https://forms.gle/aXs2v8wrWhNt667g8</a></p> <p><b>Kim</b>- will reach out to UT, identify collaborators and explore survey through UT</p>
<b>Tracking of TN Legislative Agenda Update</b>	<p><b>Abby Trotter</b> <b>Terry Jo Bichell, Vice-Chair, RDAC, All</b></p> <p>Short report from Abby, she shared short report -</p> <p>So far, 25 bills sent to LST as of last Friday</p> <p>New bills filed every day (Scope of practice, PBMs, Vaccines - all over the map)</p> <p>Sunset pharmacy advisory committee bill. Procedural,</p>	<p><b>All</b>- List all agencies introduction letter should go to in slack discussion</p> <p><b>Abby</b> - draft letter to other organizations</p>

	<p>happens every few years. Will also happen to our committee</p> <p>TNCare demonstration waiver passed last week</p> <p>Suggestion - this committee sends a letter to agencies we think are important - if they want to know about a policy, they can reach out. Could be linked to the press release. Within letter, define scope of what we want to achieve.</p> <p>This can go on TennCare letterhead as we are statutorily committed to TennCare and under the umbrella</p>	
<p><b>Website Update</b></p>	<p><b>Scott Strome, Chair, TN RDAC</b></p> <p>Logo discussion</p> <p>The wire frame for the website is complete, now needs content. Will also require maintenance. Team can do all of that.</p> <p>Abby has started some of the copy, will share with the rest of the group when they meet.</p>	<p><b>Chip Chambers, Megan Crow</b> Will ask around for graphic artists to donate time for a logo.</p> <p><b>Terry Jo Bichell, Gillian Hooker, Reginald French, Megan Crow, Abby Trotter, Dan Harder and Todd Barber</b> will meet to discuss content.</p>
<p><b>Documentation of Processes and Procedures</b></p>	<p><b>Gillian Hooker, Secretary Treasurer</b></p> <p>Lora said other committees have standard processes they follow typically, does think it would be a good idea to document ours for this RDAC.</p>	<p><b>Gillian Hooker</b> - document processes and procedure for engaging on legislation</p>
<p><b>Review TN RDAC Press Release Plan</b></p>	<p><b>Abby Trotter</b></p> <p>We have it, it has been circulated, some comments have been provided. As soon as website is activated we can send it out. (that way people will have a place to go when the link comes out)</p> <p>Survey could reference the press release?</p>	<p><b>All-</b> Provide any additional feedback on press release on slack.</p>
<p><b>Liaison Updates</b></p> <ol style="list-style-type: none"> <li>1. <b>Pharmacy Advisory Committee</b></li> <li>2. <b>Drug Utilization Review Committee</b></li> <li>3. <b>Newborn Screening</b></li> <li>4. <b>Department of Intellectual and Developmental</b></li> </ol>	<p><b>Reginald French -PAC</b> No Updates</p> <p><b>Megan Crow DUR-</b> Joined 1/12 meeting, discussed:</p> <p>-Medicaid Block grant, 10 year waiver, benefit would be that they could use the savings to put back into TennCare or TN budget. Will maintain or improve quality of program. Flexibilities in waiver - safe guard to meet 10 measurable goals. Currently setting goals. Priorities: Maternal Health, needy populations, intellectual and developmental disabilities.</p>	<p>Continue to provide updates</p>

<p><b>Disabilities</b></p>	<p>-Note that things are coming through very quickly.</p> <p>-Discussed Cover Kids transition.</p> <p>- MTM program care coordination tool is popular.</p> <p>-COVID 19 emergency relief</p> <p>-Presented RDAC - questions -what is our definition of RD? <u>How many TennCare members impacted by RD?</u> They may help us identify rare diseases that TennCare serves - This is an important question for us to answer.</p> <p>-TennCare utilization data - increasing membership. Edits and rejections are down b/c of COVID changes</p> <p><b>Rizwan Hamid</b> - Not present</p> <p><b>Terry Jo Bichell</b> - Update on recent efforts. Getting the word out that people with IDD who can't live independently will be in first category to receive vaccine - added at the last minute to 1A1 category. Word is slowly getting out. Strike event - coordinated to give vaccines for particular groups - big cities struggling to get the word out.</p>	
<p><b>Review of Action Items and Agenda Items for December Meeting</b></p>	<p><b>Scott Strome, Chair, TN RDAC</b></p>	