

## TennCare Rare Disease Advisory Council (RDAC)

Agenda (December 29th, 2020)

Present: Storme, Bichell, Hooker, Overby, Hamid, Stephens, French, Jackowski, Underwood,  
(Attendees: Trotter, ?Lane)

Absent: Callison, Tolle, Chambers

1:00-1:05 CT	Call to order and Welcome	<p>Scott Strome, Chair, TN RDAC</p> <p>Seeking to build the mission of this council aside from the duties already assigned by legislation, open to discussion</p> <p>Website being developed - UT can be the sponsor or not, open to discussion</p> <p>Abby Trotter will work on press release which will include the mission statement</p> <p>How can we help Tennesseans with rare diseases</p>
1:05-1:15	Rare Disease Patient Story	<p>Tammy Cate, Parent, East TN Sign Language Interpreter at UT, son has Duchenne Muscular Dystrophy. Son born in 2005, very sports oriented but at 4-5yo wasn't able to keep up in running in soccer. 2011 had doctor visit, noticed he had large calves. Video of son playing soccer, went to Children's, did a few tests, including watching him get up from floor, using all body parts. Went to Cincinnati Children's to confirm it was Duchenne. Mom is a carrier. She became a resource for other families. Son has been in 4 clinical trials, weekly infusions now. He has been to NIH and Ohio for treatment, because no suitable treatment here in Tennessee. She has spoken before the FDA to get approval for medications for Duchenne. Her son is currently waiting for next trial - none yet to qualify for. Power Chair has been declined by insurance. Every 6 months he has an appt in Ohio.</p> <p>Hamid asked what one thing Cate would change to reduce her burden.. Cate responded that fighting for insurance coverage is a huge burden, for infusions, for equipment.</p>
1:15-1:25	<p>Mission Statement (<a href="#">Draft circulated by Hooker</a>) Final mission statement draft: <a href="https://drive.google.com/file/d/1ok4w92bqeGxtqp-BXdu5J6S4ZKlouO5r/view?usp=sharing">https://drive.google.com/file/d/1ok4w92bqeGxtqp-BXdu5J6S4ZKlouO5r/view?usp=sharing</a></p>	<p>Scott Strome, Chair, TN RDAC</p> <p>Kim wants more focus in the mission statement. Rizwan thinks the current mission statement should be a "vision statement"</p> <p>Discussion about differentiating Mission vs. Vision</p>

		<p>vs. Goals and Objectives</p> <p>No goals and objectives listed yet for RDAC. Strome reiterates need to follow legislative priorities that we are assigned.</p> <p>Hamid wants to interview just 3-4 physicians and 3-4 families to clarify mission statement, goals and objectives. He wants to clarify what legislature wants from us.</p> <p>Strome suggests that legislature needs our expertise, as they do not know what issues are important in the area.</p>
1:25-1:30	Update from NORD RDAC Workshop	Terry Jo Bichell, Vice-Chair, RDAC Tabled report to next meeting, or via Slack.
1:30-1:50	<p>RDAC Communication</p> <ol style="list-style-type: none"> <li>1. Slack</li> <li>2. Website <ol style="list-style-type: none"> <li>a. Appoint Chair</li> <li>b. Review wireframe &amp; content outline</li> </ol> </li> </ol>	<p>Scott Strome, Chair, TN RDAC</p> <p>Brief - met with Dan Harter and team at UT to work on website. They can do a few hours initially, getting things started.</p> <p>Megan Lane could look at the website to populate it with the automatic feed of bills being considered.</p> <p>Abby Trotter,, by the end of this month could do a one-page overview of the RDAC to use as press release, but believes that someone who is actually a Council Member should take the lead.</p> <p>Website content committed to include Gillian Hooker, Reginald French, Abby Trotter, Kim Stephens, and Terry Jo Bichell to will work on content and then get it to rest of Council for review. Include Dan in meetings, and Tanya can help with scheduling.</p>
1:50-2:00	Review TN RDAC Press Release	<p>Abby Trotter will lead design of a logo for the RDAC.</p> <p>Draft is on slack for review, but we will wait until website is up before circulating (end Jan, early Feb).</p> <p>Launch it with the survey.</p>
2:00-2:10	Tracking of TN Legislative Agenda	<p>Terry Jo Bichell, Vice-Chair, RDAC, All</p> <p>We are government council and cannot lobby. We can issue expert opinions based on facts, and bring in testimony by outside experts on specific areas.</p> <p>Written update weekly can be provided via</p>

		<p>LifeScienceTN. Bio also does this. Trotter suggests these could be compiled and go to Bichell, Hooker and Stephens to flag. Otherwise all bills going through Health Committee is too many.</p> <p>Megan Owensby suggests the RDAC be both proactive and reactive about legislation.</p> <p>Hamid wants to interview 3 key physicians for their priorities.</p> <p>Bichell suggests we come up with a process for what to consider.</p> <p>Storme describes process used by RAC (?). Issues are circulated, and when 2 or more committee members vote yes, then the Council considers it. Issue will be presented by a Primary reviewer and Secondary reviewer, presented to entire council.</p> <p>Discussion about threshold, agreeing that 2 is enough. Then issue opinion based on 50% or more of councilmembers, with a written opinion or White Paper, such as <a href="#">this from DIDD</a>.</p> <p>Motion that if 2 people want to bring legislation before council, they present, 2 people need to review and then majority of our council agree to pursue with written opinion. Rizwan gave a second. Nobody opposed.</p>
<p>2:10-2:15</p>	<p>TN Rare Disease Survey Update</p>	<p>Kim Stephens leading effort. Will work across NORD and explore best pathway. Bichell to help Stephens craft plan to present to RDAC at next meeting.</p> <p>Described the PA survey, which went to the broader community, and surveyed practitioners, as well. 20 questions - 10 mins</p> <p>Suggestion to use Qualtrics from UT, but PA RDAC advised better to use independent mechanism. Survey monkey would have a minor cost but it is HIPPA compliant, and PA was able to use an IRB. Discussion on UT IRB or Western IRB. Suggestion to use <a href="http://www.geneticalliance.org/programs/biotrust/peer">http://www.geneticalliance.org/programs/biotrust/peer</a> for building registries</p> <p>If we ask about priorities and interests, no HIPPA. If we ask about disease issues, HIPPA.</p> <p>Suggestion is to wait until our website is up before launching survey. Don't launch til we have a website.</p> <p>This data from survey can identify our priorities and we should publish the info.</p>

		<p>Hamid suggested using ICD-10 codes and hospitalization rates to glean rare disease statistics rather than survey, but group informed him that most rare diseases do not have unique ICD-10 codes.</p>
2:15-2:25	<p><b>Liaison Updates</b></p> <ol style="list-style-type: none"> <li>1. Pharmacy Advisory Committee</li> <li>2. Drug Utilization Review Committee</li> <li>3. Newborn Screening</li> <li>4. Department of Intellectual and Developmental Disabilities</li> </ol>	<p>Reginald French - PAC - next meeting is Feb 11. After that will provide a better update.  Megan Overby - DUR - Only meet quarterly and Jan 12  Rizwan Hamid -NB Screening - Meet quarterly meet early next year  Terry Jo Bichell - DIDD - Meeting in January</p>
10:55-11:00	<p>Review of Action Items and Agenda Items for December Meeting</p>	<p>Scott Strome, Chair, TN RDAC</p>