

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 (February 24th, 2021)

	<i>Notes</i>	<i>Action Items</i>
Call to order and Welcome	<p>Rare disease Day is February 28th.</p> <p>Chip Chambers wrote an Op Ed for the Tennessean that will run on 2/28.</p> <p>A bridge in Nashville will be lit up in honor of rare disease.</p> <p>Register for NIH Rare Disease Day Speakers at NIH if you can.</p> <p>Global Genes will be hosting events as well.</p> <p>The EveryLife Foundation has a number of federal advocacy events planned.</p> <p>On Friday, Scott Strome will be presenting at 12:30 on the NORD call to talk about what we're doing in TN.</p>	Participate in Rare Disease Day activities.
Rare Disease Patient Story	<p>Jessica Shoup shared her experience with Klippel Trenaunay syndrome.</p> <p>She was misdiagnosed when she was young, and had other health issues including bleeding and iron deficiency.</p> <p>It wasn't until she was 30 that she received a diagnosis</p> <p>There is very little known about KT and there have been challenges to getting treatment. She is insured w/ Medicare as an individual w/ a disability.</p> <p>Access to treatment has been a challenge. In talks, via email and online w/ clinics in other regions that will treat her disease, but she must travel to do that.</p> <p>She advocated for funding for research and clinical trials. It's a very debilitating condition and resources are needed.</p> <p>Genetic testing has not been done, but it's unclear whether medicare would cover this. No one has recommended this.</p>	
NORD Representative	<p>Rose Avellino Gallagher</p> <p>NORD is tracking step therapy legislation in TN. This bill provides more patient protection when step-therapy is used. Step therapy requires that a patient try a cheaper drug before advancing to a more expensive one.</p> <p>There has been payer pushback on the bill to put protections in for step therapy and last year it didn't get through because of fiscal notes</p>	<p>Identify patient stories of individuals who have been challenged by step therapy policies and share with coalition</p> <p>We will plan to invite Rose Gallagher back for more</p>

	<p>Rare disease patients are often getting stepped for a treatment that is intended for a comorbidity, so narrowing the bill could also have drawbacks. In some cases, step therapy can do more harm than good.</p> <p>NORD is also tracking the copay accumulator bill in TN (H.B. 619).</p> <p>Patients aren't able to count manufacturer copayment assistance toward annual deductibles or max-out-of-pocket costs.</p> <p>Other states are weighing in on issues through a yearly report or annual report - issues report with a lot of policy recommendations. E.g. in AL - they made recommendations in the report</p> <p>In MN - they work on whitepapers for specific policies.</p> <p>In NH- they are more reactive and weigh in on a regular basis. Informally</p> <p>In NC and PA put out yearly issue-based reports on similar issues. PA includes lots of policy recommendations in yearly reports. NC writes individual white papers on specific issues</p> <p>The TN legislation was written broadly - we can advise any government agency. It's ours to own. We get to define what we're going to be involved in and how we're going to approach that. We will also use the survey to inform that.</p>	updates.
<p>TN Rare Disease Survey Update</p>	<p>Kim is updating and editing the survey and it's ready to go.</p> <p>Suggestion at this point is to leave as a google survey and publishing as a white paper. Consider doing it a second time w/ IRB approval later this year.</p>	<p>Kim will work w/ Abby to get it on the website and distribute it.</p> <p>All committee members will be asked to help distribute</p>
<p>Tracking of TN Legislative Agenda Update</p>	<p>Terry Jo Bichell proposed doing a biannual report at the beginning of the legislative sessions.</p> <p>Then we can have a process for a nimble response to individual bills. Issues preassigned to RDAC members.</p> <p>A long list of legislation has been posted in the slack channel for folks to provide feedback on. And here.</p> <p>There is a coalition around PBM reform that is forming. They are looking for stories.</p> <p>Friday March 5th, event on gene-editing and gene-therapy</p>	<p>Review legislation posted in slack weigh in on bills.</p>

	and value based purchasing around that.	
Review of RDAC Logos	Approved the logo w/ edits	Megan Crow will update the logo
Website Update	Content has been delivered Website is being finalized - content being added	Logo will be shared with the web team Gillian Hooker will share minutes and agendas with Alan for posting
Review TN RDAC Press Release Plan	Press release will go out once the website is up	Abby will send press release out.
Liaison Updates <ol style="list-style-type: none"> 1. Pharmacy Advisory Committee 2. Drug Utilization Review Committee 3. Newborn Screening 4. Department of Intellectual and Developmental Disabilities 		All liaisons please share updates
Review of Action Items and Agenda Items for December Meeting		On the next call, Dr. Ward will present a physician point of view on rare disease in the state.