

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 March 24th, 2021

RDAC Members In Attendance: Scott Strome, Megan Crow, Clay Callison, Chip Chambers, Terry Jo Bichell, Reginald French, Kim Stephens, Suzanne Rock, Rizwan Hamid, Lora Underwood

Other Attendees: Jewell Ward, Tanya Hendricks, Marisa, Todd Barber

	<i>Notes</i>	<i>Action Items</i>
Call to order and Welcome	Scott Strome, Chair, TN RDAC welcomed everyone - called the meeting to order.	
Rare Disease Provider Perspective	<p>Jewel Ward, MD, PhD, UTHSC</p> <p>Presented on the history of treatment policy work within TN for patients with Inborn Errors of Metabolism (IEM).</p> <p>She shared a long history of challenges in advocating for patients who need specialized diets and supplements to avoid major metabolic crises and malnutrition.</p> <p>Too, often, oral preparations have been categorized as foods, leading payers to deny coverage.</p> <p>In particular, getting treatment approved for outpatient treatment is a problem and for some patients can cause a major delay in discharge.</p> <p>Companies making the products - will sometimes provide a bridge amount to try to get the patient home and until coverage is approved.</p> <p>Coverage issues occur on both the private payer side and on the TennCare side.</p> <p>In some cases, treatments are classified as durable medical equipment, which leads to a bottle neck - payers see an unusual preparation, don't see it on the list of things they approve, and deny it.</p> <p>The Genetics Advisory Committee/ Newborn Screening Program has submitted cases of harm and overpayment to the state for review.</p> <p>The State of Michigan has updated their policy in a way that would be useful to TN. Dr. Jewell provided the RDAC with a</p>	<p>GWH will circulate Dr. Jewell's documents to the RDAC.</p> <p>Committee will consider how to make financial arguments for policies in the rare disease space.</p> <p>Consider advocating for policies like michigan policy</p>

	<p>copy of the MI policy</p> <p>Other RDAC members weighed in from their experience:</p> <p>Clay Callison - has gone to court on behalf of patients - there are times when patients don't meet criteria to stay in the hospital, but also don't have the support to go home. Having someone to look at the big picture would be helpful.</p> <p>Chip Chambers - How can we make headway to get finance people to do the cost benefit analysis? -We need more financial analyses on the state - because they're not specialists - it's a powerful thing to approach the leadership of the plan with black and white numbers.</p> <p>Terry Jo Bichell asked - who's responsibility is it to show how much these things are costing the state? How can we find these resources?</p> <p>Rizwan Hamid - It's a conundrum for physicians who care for these patients- they are overstretched - for 5-6 million people, there are only a handful of metabolic doctors - usually in clinic and after clinic - people like Jewell or John - on their personal time - physicians not all suited to make these financial arguments.</p> <p>Recommendation from this committee could be to identify the person or division who calculates those costs to the state such as hospitalization vs. medical food costs.</p>	
<p>The Role of the TNRDAC in Legislative Policymaking</p>	<p>Scott Strome, Chair, TN RDAC</p> <p>Following up on previous discussions of what the role is for the RDAC in engaging the legislature - it led to discussions</p> <ul style="list-style-type: none"> A) How do we get an adequate amount of information in a timely way so that we understand all sides of issues? B) How do we begin to take the pulse of legislatures so that we can support policies around rare disease but also within our mandate as a committee? <p>Abby Trotter- Reviewing Committee charter we're asked to be an advisor back to TennCare's PAC and DUR specifically about things that they are doing, drugs that they are looking at that affect rare diseases</p> <p>To be an advisor to many state agencies on the impact of rare diseases in the state.</p> <p>We need to have good data to back up the advice that we are giving. How are we going to get the data so that when we weigh in on a bill, we have research and data and our own perspective behind that.</p>	<p>The group will explore ways to create a white paper with the findings of our survey and committee perspectives to speak to major rare disease issues in the state and that we've heard about this year.</p>

<p>TN Rare Disease Survey Update</p>	<p>Kim Stephens, RDAC Member</p> <p>The survey is ready to go, waiting for website and press release</p> <p>Plan for circulation - we will use committee members, the press release and social media to push the survey out.</p>	<p>A. Trotter will finalize the press release</p> <p>K. Stephens will notify committee members once survey opens</p> <p>All - Circulate survey once released</p>
<p>Website Update and Press Release Plan</p> <p>tnrdac.org</p>	<p>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</p> <p>Website is up</p> <p>TNRDAC.org</p> <p>Discussion of how to create awareness of meetings and to make sure the public has access to the meetings.</p> <ul style="list-style-type: none"> - Create a brochure <p>Lora will deactivate the state page - keep a brief overview of what the RDAC is and provide a link on that page to our page.</p>	<p>T. Hendrics and M. Alston - For For future meetings, post an attendee link on the website</p> <p>Send a panelist link to all RDAC members.</p> <p>M. Crow will explore creation of a brochure about the RDAC.</p> <p>L. Underwood will deactivate state page and create a link to our full website.</p>
<p>TN Pharmacy Advisory Committee</p>	<p>Reginald French, RDAC Member</p> <p>For PAC - they have drugs come up where no one has any expertise on their committee, and they will need guidance- the PAC committee releases agenda early on - are there drugs that we can provide additional expertise on - they create criteria for coverage of drugs.</p> <p>PAC reviews drug classes and new drugs - when a new drug comes out - within 6 months bring the criteria to the committee so they can vote on it</p> <p>Every 2-3 years they review every therapeutic class that they cover They accept background information on the drug in advance of the meeting</p> <p>The RDAC will review upcoming agenda and identify any drugs coming up for review pertinent to rare disease</p> <p>Next meeting:</p>	<p>R. French will submit a request to speak about Dojolvi on the next PAC committee meeting.</p>

	<ul style="list-style-type: none"> • DOJOLVI - long chain fatty acid oxidation disorders • GIMOTI - diabetes • GLOPERBA - gout • HEMADY - multiple myeloma • INQOVI - leukemia • LAMPIT - chagas disease • RINVOQ - rheumatoid arthritis • RETEVMO- small cell lung cancer 	
<p>Liaison Updates</p> <ol style="list-style-type: none"> 1. Drug Utilization Review Committee 2. Newborn Screening 3. Department of Intellectual and Developmental Disabilities 	<p style="text-align: center;">4. Megan Crow, RDAC Member</p> <p>Provided DUR update</p> <p style="text-align: center;">5. Rizwan Hamid, RDAC Member</p> <p>R. Hamid will introduce to GAC/NBS this month - and provide a report on our next call</p> <p style="text-align: center;">6. Terry Jo Bichell, RDAC Member</p> <p>T. Bichell is being interviewed to be a formal member of the council and will continue to serve as a liaison - she will learn a lot about how they provide guidance and review issues - our state was the first state to offer the COVID-19 vaccine to people with intellectual and dev.</p>	
<p>Closing</p>	<p>Scott Strome, Chair, TN RDAC</p> <p>We will need to look at survey data and really develop the tenets of this committee, setting the foundation of who we want to be</p> <p>Important discussions re: concerns around vaccines and requirements around vaccines that have bled into areas of childhood vaccination that's really concerning to many in the healthcare field</p>	