

TennCare Rare Disease Advisory Committee (RDAC)

Minutes (November 25th, 2020)

Members In Attendance: Scott Strome, MD, Terry Jo Bichell, PhD, MPH, Gilian Hooker, PhD, ScM, Lora Underwood, PharmD, Rizwan Hamid, MD, PhD, Suzanne Jackowski, PhD, J. Clay Callison, MD, Megan Overby, RN, Chip Chambers, MD, Reginald French, Kim Stephens, PhD

Non-Members Present: Todd Barber, Dan Harder (UTHSC) Abby Trotter, Executive Director, Life Science Tennessee

	Notes	Action Items
Call to order and Welcome		
RDAC Communication Mechanisms	<p>We will be using slack to communicate with one another All members watched a quick demo.</p> <p>The desktop version is recommended.</p> <p>Dan Harder will send out links to everyone to get logged on with the email you used for this Zoom.</p> <p>The creation of an RDAC website was explored. It would be a good way to provide resource links, solicit input from the community and advertise the RDAC to the state.</p>	<p>Establish slack channels/log ins- Dan Hardr</p> <p>Establish Slack Accounts - ALL</p> <p>Explore website creation - Strome, Harder, Barber</p>
Review of Member Disclosure Forms and Relationships	All members reviewed CO submitted, R Hamid and L Underwood no conflicts to disclose	<p>Keep COI form up to date moving forward - ALL</p> <p>Finalize 11/2020 Spreadsheet for posting on the website - Hooker</p>
Review of Member Priority Survey	Reviewed member priority survey	Create a tracking sheet of member priorities. - Hooker
Review of RDAC Activities in other states	<p>Dr. Bichell presented an update on other state RDACs and their activities. Current activities include:</p> <ul style="list-style-type: none"> - Advising Drug Utilization Review - Advising state administrators - Working on state-wide collaborative projects - Applying for grants to support outreach work - Advising on state laws and regulations - Promoting RD awareness 	Consider attending NORD workshop - ALL

	<p>There is a workshop for NORD - Wed 12/16 - 12:30-4:30 ET - will attempt to get invites for all members.</p>	
<p>Open Discussion about Year 1 Priorities</p>	<p>In the first year, we need activities that 1) build a successful foundation for the committee and 2) meet goals established by the committee consistent with the mission of the RDAC.</p> <p><u>Foundational activities</u></p> <p>1) Establishing a mission, vision and goals statement</p> <p>2) Establish an agenda for educating the committee on the state of rare disease in TN, could include:</p> <ul style="list-style-type: none"> - Survey of rare disease groups - Survey of patients - Review of TN state utilization patterns - Newborn Screening program - Guest speakers/presentations <p>3) Outreach and communication about the RDAC to state lawmakers and other state groups.</p> <p><u>Goals:</u></p> <p>1) Serve as a consulting body for topics brought to the RDAC by TennCare and state lawmakers</p> <p>2) Identify topics of importance to TennCare and state lawmakers. Topics may be identified in the following ways:</p> <ul style="list-style-type: none"> - Surveys - State-policy updates <p>3) Other?</p>	<p>Develop a one-page overview with our mission vision, goals and priorities for review at the next meeting - Strome, Bichell, Hooker, Trotter</p> <p>Consider ways to efficiently gather information and educate the RDAC on the rare disease landscape in TN - ALL</p> <p>Consider a press release about the RDAC to educate state constituents about activities ALL</p> <p>Consider using the LST caucus updates as updates to the RDAC on relevant bills from legislative agenda - Trotter</p>
<p>Review of Liaison Roles and Liaison Update</p>	<p>The RDAC appointed the following to liaison roles. Each liaison will attend the meetings of these groups and provide a report back when appropriate at the next RDAC meeting.</p> <p>Liaison roles are as follows:</p> <p>PAC - Reginald French (Dr. Bichell attended the recent meeting to educate the PAC about the RDAC)</p> <p>DUR - Megan Overby</p> <p>NBS - Dr. Rizwan Hamid</p> <p>DIDD - DR. Terry Jo Bichell</p> <p>When new liaison opportunities open up, RDAC members will reach out and offer to serve as liaisons and the committee and consider and approve if appropriate.</p>	<p>Liaisons will notify executive committee of any updates they have prior to each call so that they can be added to the agenda. - French, Overby, Hamid and Bichell</p> <p>Educate liaison committees about the RDAC mission and goals - Overby, Hamid and Bichell</p>