

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.

Agenda March 23rd, 2022

RDAC Members in Attendance: Terry Jo Bichell, Gillian Hooker, Kimberly Stephens, Chip Chambers, Clay Allison, Reginald French, Lora Underwood

Others in Attendance; Sharon Terry, *Genetic Alliance*, John Fox, *Illumina*, Katherine Peatross, *Patient Advocate*, Ashley McMinn, Todd Barber

Call to order and Welcome	Terry Jo Bichell, RDAC Vice-Chair	
<p>Update on iHope Project https://ihopenetwork.org/</p>	<p>Sharon Terry , CEO Genetic Alliance</p> <p>Discussed her own family’s journey to a diagnosis and her work in Genetic Alliance.</p> <p>Cited 250 M+ people w/ genetic disease world wide (vs. 212 M w/ Malaria, 40 M w/ HIV)</p> <p>GAO report to congress las fall showed that genetic diagnosis provides a pathway to hope</p> <p>Illumina ran iHope for 6 years, now they’ve started iHope Genetic Health</p> <p>In the original iHope, 60% of those sequenced had a change in management</p> <p>Plan is to scale to 40K per year over the next 5 years, they hope it will be higher</p> <p>All data will go to Luna where individuals will own their own DNA, also be able to share EHR data, using the platform to match to either clinical research or pharma trials.</p> <p>Enabled by a gift from illumina of 120M in reagents.</p> <p>They are still raising money for overhead, support, training, operational support. They have an RFI out on the street.</p> <p>GA also working on the bill in congress to cover genome sequencing in several states for medicaid beneficiaries.</p> <p>Part of the RFI - asking families to register - share their denials - connecting</p>	<p>RDAC will keep in touch with iHope Genetic Health in the event there are collaboration opportunities with the TN Rare Disease Diagnostics Program</p>

	<p>them to pathways for assistance</p> <p>Labs will apply through an RFP process -connected to clinical sites</p> <p>How do people find out about this? Lots of pathways, thought it's hard in the US to get through the noise. They will use social media outreach, ways to disseminate information, relying on the labs, their relationships with clinical sites, professional societies - Connections to AAP, ACMG, ASHG, PBS Newshour is doing a piece. Also possible to directly contact Genetic Alliance</p> <p>Kim Stephens - asked about how RUSP, advocacy groups will tie into iHope Genetic Health and registries. Discussed PEER - Promise for Engaging Everyone Responsibly</p>	
<p>TN Expanded Genomic Diagnostics Program update / TN Rare and Undiagnosed Disease Network Update</p>	<p>Rizwan Hamid, RDAC Member Scott Strome, RDAC Chair Chip Chambers, RDAC Member Terry Jo Bichell, RDAC Vice-chair</p> <p>Would the iHope project be a good fit/ partner for the TN Undiagnosed Disease Network?</p> <ol style="list-style-type: none"> 1) Using their preferred labs, providers 2) For folks who do not have coverage 3) Education of PCPs <p>Discussed challenges of engaging PCPS</p> <p>Discussed genetic counselors and access to genetic counselors</p> <p>Discussed entry requirements into the program</p> <p>Name is still under discussion.</p> <p>Will need to check with Ashley Reed.</p>	<p>Consider one more iteration of the project plan</p> <p>Plan outreach to relevant stakeholders</p>
<p>RDAC Step Therapy Working Group Update</p>	<p>Reginald French, RDAC Member Megan Crow, RDAC Member Kim Stephens, RDAC Member</p> <p>R. French attended the meeting where Step therapy was discussed, it passed in the house, is now in the senate. For the past 3 years it did leave the house and did not get through the senate.</p>	<p>R. French will keep us updated if the bill progresses</p>
<p>Newborn Screening Opportunities Update</p>	<p>Kim Stephens, RDAC Member Rizwan Hamid, RDAC Member Abby Trotter, LifeScienceTN</p> <p>K. Stephens is scheduled to meet with screening advisory committee. Addressing questions related to implementation.</p>	<p>K. Stephens, R. Hamid and A. Trotter will continue to meet to strategize a path to RUSP alignment in Tennessee</p>

<p>Brief Updates</p> <p><i>Term Limits / Succession</i></p> <p><i>Pharmacy Advisory Committee Update</i></p> <p><i>DUR Update</i></p> <p><i>Newborn Screening / Genetics Advisory Committee Updates</i></p> <p><i>Department of Intellectual and Developmental Disabilities</i></p>	<p>Terry Jo Bichell, RDAC Members S. Strome and L. Underwood received their new reappointment letters. Our proposed new member, David Finkel, should have received his as well.</p> <p>Reginald French, RDAC Member Lora Underwood, RDAC Member Next meeting is in May. L. Underwood will send R. French the tentative agenda prior to its official upload date on the website. He will review and he and Lora will flag anything that might be of interest to the committee. He will also circulate the agenda to the RDAC.</p> <p>Megan Crow, RDAC Member The Pharmacy director, Ray McIntyre is retiring at the end of June. L. Underwood will move into that position and managing the DUR meetings.</p> <p>Rizwan Hamid, RDAC Member Will keep us updated on developments with the newborn screening in TN.</p> <p>Terry Jo Bichell, RDAC Vice Chair Discussed the council and that there's a lot we can learn from them. The next meeting is in a month a half</p>	
<p>Review of Action Items and Agenda Items</p>	<p>Terry Jo Bichell, RDAC Vice-Chair and Gillian Hooker, RDAC Secretary Treasurer</p>	