



## **North Carolina Rare Disease Advisory Council Meeting Minutes**

### **Thursday, August 31, 2017**

### **Building 4, Suite 50, 6340 Quadrangle Drive, Chapel Hill**

The following council members were in attendance:

Bruce Cairns  
Tara Britt  
Sharon King  
Rufus Edmisten  
Brenda Nielsen  
Aravind Asokan  
Mike Knowles  
Loren Pena (for Vandana Shashi)

Others in attendance were:

Sandi Lehrman  
Stephen Lehrman  
Cindy Powell  
Rick Williams

1:00 – 1:15                    Welcome & Update of Grant Funding    Bruce Cairns  
Bruce announced the 2M ROI grant we received in collaboration with Pharmacy & NCSU Computer Science. We also discussed the upcoming NSF grant submission that went out on 9/18/17.

1:15 – 1:25                    Introduction of Guests                    Tara Britt  
   & New member

All of non-council members introduced themselves and why they were interested in supporting the council’s initiatives. Dr. Cindy Powell announced her new role as a member of the Advisory Committee for Heritable Disorders in Newborn and Children. This committee makes recommendations to the U.S. Secretary of Health and Human Services

about new conditions to add to the Recommended Uniform Screening Panel that guides states in implementing conditions to public health newborn screening programs.

1:25 – 2:00	NC Rare Disease Advisory Council & NC Rare Disease Innovations Institute discussion	Tara Britt, Rick Williams & Rufus Edmisten
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Rick discussed the NC Regional rare disease community networks from the non-profit direction. Tara is coordinating these efforts for the council with the legislators. Rick said we would start with the Eastern NC community effort and Tara is coordinating this visit with Senator Pate. Rick will also work with John Chaffee who spearheads economic development in this region.

Rufus is helping to coordinate this and he also reminded us that we are here to serve ALL the people of NC.

Rick also talked about the patient information portal & said Sharon would elaborate more on this. Rick also talked about the patient information session the non-profit coordinated and the comments from the caregivers about feeling their feeling of isolation and the urgency they feel.

2:00 – 2:10	NC DHHS Updates	Mark Benton
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2:10– 2:40	Patient Advocacy & Task Force	Sharon King & Stephen Lehrman
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Sharon discussed the portal and talked about the 1<sup>st</sup> patient survey. We are waiting now on the outcome of that survey and then will send over to Mike Kowolenko’s group at NCSU to apply the data analytics.

Bruce said this would be “Data with a Heart” and that we must stay true to our mission which are all of the Sharon’s and Taylor’s in NC.

Tara asked Sharon to discuss the Task force. Sharon suggested the council form a task force made up of subject matter experts that could advise the council regarding matters that are urgent for the rare disease community and she and Tara suggested that Stephen Lehrman lead this task force. Sharon made a motion to the council that we form a task force and that Stephen would lead this. Rufus seconded that motion. Stephen and Sandi Lehrman as well as Sharon King will serve on this and will bring in other experts as needed. Rufus made a motion to make newborn screening the first topic the task force addresses and Tara seconded that motion. The council approved 100%. Patients and advocates have been asking what the council is doing for them so the task force is viewed as an action force for that community.

Sandi asked if there was screening for HIV and we had a discussion about that.

Rufus said we also need to be aware of any politics surrounding our topics.

Bruce brought up the micro-patient concept and discussed that most do not have an understanding of what caregivers really go through.

2:40 – 3:00

Discussion

Council

Loren asked how the task force could find best practices. Which states are doing what in regards to rare disease, look for models.

Discussion around technologies involved to keep up with newborn screening.

Maybe talk to Randall Williams in his role as Secretary of NC DHHS since Missouri is a progressive state for NBS. Also, Tara will follow up with him in regards to the Surgeon General to see if Rare Diseases could become a new campaign nation wide.

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Questions? Tara Britt, 919-417-6130