



**North Carolina Rare Disease Advisory Council Meeting Minutes
Wednesday, October 5, 2016
Building 4, 6340 Quadrangle Drive, Chapel Hill**

In attendance were: Dr. Michael Knowles, Dr. Randall Williams, Dr. Kelly Kimple, Dr. Vandana Shashi (via phone), Brenda Nielsen, Sharon King, Dr. Bruce Cairns and Tara Britt. Dr. Aravind Asokan was absent for this meeting due to prior commitments.

2:00–2:30 Welcome, Updates, Discussion Bruce Cairns & Council

Bruce welcomed the group and Randall introduced the new member from NC DHHS, Kelly Kimple from UNC Healthcare.

Bruce gave an overview of the importance of our partners and collaborators such as NCSU Computer Science with the NSF Big Spokes Data Proposal. He also touched on the collaboration with NC DHHS in regards to the All Payer Claims Database and the importance of the rare disease integration.

He also mentioned the future partnership with the School of Pharmacy at UNC.

2:30-2:45 NC DHHS Updates Randall Williams

Randall talked about the majority of our clinicians coming from the public universities. He also emphasized that after visiting all 100 counties in NC, the importance of advocating for the people in rural areas in NC. He brought up the #1 focus for NC DHHS this year would be the Infant Mortality Initiative. The target of this initiative would be that each pregnancy would be a planned pregnancy so that women can get healthcare for the pregnancy from the beginning or even before. Randall also mentioned there are 3 counties in NC with no obstetricians. Most of the medical school graduates choose to locate to larger cities with major medical hubs and how problematic that is for the rural areas. He was excited to present that starting in 2018, there will be a MDBA program that will be taking in 18 in NC.

They will return to one of the 31 counties that are in the rural areas with limited access to healthcare.

He talked about NC being recognized as the Innovate thought leaders for the whole country and the importance to Humanize rare diseases. Mike, Vandana and Brenda also echoed their support of the rural areas and access to good healthcare.

There was a group discussion of the importance of good healthcare access to the rural areas and how we could improve the connection with the rural counties and major medical centers. Rural medicine was discussed and how we could use AHEC and others regarding data in urban areas and rare disease

Bruce reminded the group of this mission of the council which is to serve the people of the state of NC and that means all of the people in NC.

Rufus completed this discussion with the personal story of a scholarship recipient from his foundation, Extra Special Super Kids, who support kids who come from rural backgrounds so they can go to college. One of these kids who came from humble beginnings has now started Med School at UNC CH.

2:45-3:05 NSF Proposal, Partnerships Tara Britt & Council
Website & Future Events/
Future Council Meetings/Discussion

Tara talked about the excitement & details around receiving the NSF Planning Proposal Award to Build a Big Data Spoke with NCSU Computer Science. NCSU is committing resources beyond the grant and Tara meets with 2 faculty each Monday to work towards to the big picture which is building a Big Rare Disease Observatory that will have data regarding patient registries, data that clinicians and researchers can access, data for NC DHHS and the state. We would like for this to be a data hub that the rest of the US could hopefully implement. We are working closely with NC DHHS and NIH regarding this. Tara also explained the connections she has made in the rare disease community in and out of NC in regards to Pharma, Biotech, Foundations & patient advocacy groups. The website is a reflection and ongoing work in progress which has incorporated much of their feedback.

Tara discussed a future Big Rare Disease Day symposium/conference event that will take place in late 2017 or early 2018. She and Sharon are working on this with the previous event planner in Pharma, NC Biotech and NC Bio. More information will follow.

3:05-3:15 Patient Advocate Updates Sharon King

Sharon talked about her trip to Global Genes symposium. She said the conference had several main themes including Data and that being patient centric. She also discussed the fact that other attendees there referred to NC as the biggest “missed opportunity” in regards to so many jobs in the rare disease fields are leaving for Boston when they should be staying in NC/RTP.

3:15-3:40 Clearinghouse Legislation Rufus Edmisten

Rufus brought up the Clearing House legislation that Representative Carney and Senator Pate have asked us to submit with the next legislative session. Rufus explained how important to make sure this was not proprietary. He asked Tara to prepare a specific budget and prepare the legislation to submit to he and Randall. Randall said this would be directed to NC DHHS and he would distribute to UNC as budgeted. Rufus and Randall will work with Andy Willis at UNC regarding this.

3:40-4:00

General Discussion/Input/ideas

Council

There was a group discussion from all regarding the importance of data and the various categories regarding rare diseases.

Questions? Tara Britt, 919-417-6130