

Rare Disease Advisory Council
Organizational Meeting Minutes 10/18/19

Present: Rep. Marsh, Rep Osborne, Dr. Sai Cherala, Dr. Angela Shepard, Dr. Mary Beth-Dinulos, Krista Gilbert, Dr. Laura Landerman-Garber, Robert Stoker

Called in: Dr. Elijah Stommel

Absent: Sen. Rosenwald, Dr. Richard LaFleau

Also present: Paula Minnehan, NH Hospital Assn

Rep. Marsh called the meeting to order at 3pm.

The Council elected Rep. Osborne Vice-Chair unanimously.

Rep. Marsh said he had not distributed the minutes of the organizational meeting due to internet issues. We will approve minutes next month.

Krista Gilbert presented the document “State Rare Disease Councils: Stengthening the Patient Voice in Government” which will be posted to the committee website. Discussion ensued.

Dr. Shepard discussed data bases. We have no funding to set up a registry. She discussed grants.

Dr. Stommel said we could collect data on all rare diseases in NH.

Dr. Cherala said the cancer registry costs 1M/yr and is funded by a CDC grant.

Dr. Shepard said existing registries are disease based and maintained by nonprofits.

Mr. Stoker volunteered to get info as to what data bases currently exist.

Dr. Stommel said DHMC could use the ICD codes on the NORD database to extract data from their EPIC database and volunteered to look into this.

Dr. Cherala reminded us that DHHS has hospital discharge data and newborn screening data.

Krista Gilbert will see if a Connecticut RDAC person might want to come to one of our meetings.

Dr. Shepard discussed step therapy. NHMS may be working on a bill. She will report back.

Mary Beth- Dinulos is on the Youth Sudden Death Committee and offered to monitor Rare Diseases there.

Dr. Stommel discussed a possible ALS registry, which he want to do in conjunction with Mass. Mass has not yet established a RDAC. He heard estimated cost of \$200,000 for such a registry. Mary Beth-Dinulos said perhaps DHMC could do this. Dr. Stommel will make inquiries of Mass colleagues about doing this together.

Meeting adorned at 3:50pm

Respectfully submitted, Rep. Marsh Chair