

## Rare Disease Advisory Council Meeting Minutes

6.25.24

Senator Poore called the meeting to order at 10:36 am. Members present included Representative Griffith, Andrew Babb, Cristine Vogel, Dr. Olubusola Ogulade, Zohra Ali-Khan Catts, Dr. Stephen Flachek, Dr. Stephanie Guarino, Dr. Kelvin Lee, Janice Meyer, Ifran Patel, Dr. David Tam, Dr. Karen Gripp, and Jon Hawayek. For a list of guests present, please see the attendance list below.

Senator Poore welcomed all and introduced a video from the Lt. Governor. In the video the Lt. Governor addressed the panelists and the importance of the Council's establishment. Lt. Governor Hall-Long expressed an eagerness for future meetings.

Senator Poore moved to the introduction of Council Members. Senator Poore stated her involvement as the state senator for the 12th district and sponsored the legislation for this Council.

Representative Griffith stated she is the state representative for the 12th district. She is also the parent of someone with a rare disease. Representative Griffith expresses her excitement for being a member of the council.

Andrew Babb introduced himself as a pharmacist working for Biotech Pharmacies. Babb has worked with thousands of patients with rare diseases to date. Babb works in specialty pharmacy and was nominated by the Delaware Pharmacist Society.

Dr. Stephanie Guarino introduced herself as a lifespan hematologist, oncologist, and researcher. Dr. Guarino is the medical director for adolescent and young adult oncology as well as the director for the comprehensive adult sickle cell program at Christiana Care. Dr. Guarino's career focuses on pediatric malignancies and sickle cell which are all rare diseases.

Dr. Karen Gripp introduced herself as a pediatrician and medical geneticist at Nemours. Dr. Gripp encounters patients daily with rare diseases.

Jon Hawayek introduced himself as the Head of State Government Affairs for Spark Therapeutics. Spark is the first company to get FDA approval for gene replacement therapy for a rare disease that affects vision in a small number of people. Hawayek has been appointed and sits on Rare Disease Advisory Council's (RDAC) in New Jersey, Pennsylvania, New York, South Carolina, and Florida.

Dr. Stephen Flachek introduced himself as a pediatric neurologist at Nemours. Dr. Flachek has practiced there for 25 years and has experience with genetic diseases and neurological disorders. Dr. Flachek is working alongside Dr. Gripp and a group of medical professionals to research a rare disease. Dr. Flachek was nominated by the Delaware Academy of Medicine.

Zohra Ali-Khan Catts introduced herself as the Director for Genetic Counseling Services at Christiana Care Health Systems. Catts, as a genetic counselor, sees patients with rare diseases all the time. Catts consults with nicu, prenatal genetics, cancer genetics, neuro genetics, and cardiovascular genetics.

Dr. Olubusola Ogunlade introduced herself as a physician practicing for 10 years at the Eastern Shore and in Delaware. Dr. Ogunlade is board certified in gynecology. Dr. Ogunlade is board-designated in pediatric and adolescent oncology, and minimally invasive gynecological surgery. Dr. Ogunlade is the Chief Physician of the Department of Public Health from the Office of the Medical Director.

Jan Meyer introduced herself as a retired Registered Nurse who worked for 23 years. Meyer is a rare cancer patient who has a form of cholangiocarcinoma. Meyer was a caregiver for her mother who had the same cancer. Meyer's nephew also has a rare disease. Her nephew also has a rare disease. Meyer is excited to work on the council and is looking forward to making a difference for all cancer patients in Delaware.

Ifran Patel introduced himself as a resident of Newark, Delaware. Patel is a caregiver for two kids with a rare metabolic disorder. Patel himself is a patient having recently been diagnosed with the rarest form of MMA. Patel has worked with Senator Poore and other legislators over the past 10 years regarding legislation surrounding rare disease. Patel is a 3-year NORD ambassador for the State of Delaware.

Dr. Kelvin Lee introduced himself as faculty of the University of Delaware. Dr. Lee works in the chemical and biomolecular engineering department. Dr. Lee has been leading a public-private partnership focused on biopharmaceutical manufacturing. Dr. Lee understands the technology and different therapies for manufacturing and the difficulties it brings getting therapy to patients.

Dr. David Tam introduced himself as the 4-year president and CEO at Beebe Healthcare in Sussex County, Delaware. By training, Dr. Tam is a pediatric neurologist. Dr. Tam has experience with legislation for healthcare as he was the Chief Operating Officer for TriCare for 2 years focusing on rare diseases.

Cristine Vogel introduced herself as the Director for the Office of Value Based Health Care Deliveries within the Department of Insurance. Vogel was designated by Commissioner Navarro, and is honored to be in attendance.

Senator Poore thanks everyone for introducing themselves and reiterated the importance of this council.

Senator Poore moves to the election of a council chair on the Agenda. There is confirmation that quorum has been met with all 14 council members present. Representative Griffith nominates Senator Poore as chair. Babb seconds the motion. All in favor and all approved. Senator Poore is now the Chair of the Rare Disease Advisory Council.

Chair Poore confirmed everyone got a copy of the draft bylaws. Chair Poore asked for an individual review of them and they will be voted on at the next meeting. Council members have between now and the next meeting to make the adjustments. An email should be sent with any revisions or confirmation of approval. Hawayek asked for consideration of changing the 3-year report to an annual report. Chair Poore recommended a shared file to all RDAC documents. Dr. Guarino expressed difficulty with accessing google documents due to firewalls. Dr. Gripp seconded Dr. Guarino's concern and expressed uncomfotability with using personal email. Meyer suggested an email specific to the RDAC. Chair Poore tabled the shared file and it will be addressed at the next meeting.

Moving to public comment, Chair Poore raised attendee Candace Esham to speak. Esham stated she has a rare disease – a neurological disease that is very painful. Esham has had many misdiagnoses and failed to get referrals to be seen. Esham eventually won a lottery for a neurology appointment at Christiana Care. Esham was properly diagnosed, but wanted a second opinion and was discouraged to do so. Esham went to Johns Hopkins and was given the option of surgery. Esham gives this surgery credit for saving her life. Esham stresses the importance of continuing to partner with patients.

Dr. Gripp recommends the introduction of ordering appropriate testing for rare disease patients with little interference from insurance companies and insurance companies paying for it.

Ifraan asked for clarification in sharing the meeting with others to increase the audience.

Chair Poore suggested an in-person meeting for the next RDAC meeting. A doodle poll will be sent out to secure the next meeting.

Chair Poore asked for a motion to adjourn the meeting at 11:10 am. The motion was made by Dr. Gripp and seconded by Representative Griffith.

Respectfully submitted by:

Jalen Rogers

**Attendance List:**

- Sandy Royer
- Candace Esham
- Eric Zubrow
- James Dechene
- Keith Warren
- Jen Rini