
Meeting Minutes

Rare Disease Advisory Council

September 25, 2019

Call to order

The inaugural meeting of the **Minnesota Rare Disease Advisory Council** was called to order on **September 25, 2019 4-5:30**. Those present:

- Dean Jakub Tolar
 - Erica Barnes
 - Paul Orchard
 - Art Beisang
 - Abigail Miller
 - Barbara Joers
 - Karl Nelsen
 - Soraya Beiraghi
 - Christine Kiel (administrative support)
 - Janet Zielgler
 - Srijoy Mahapatra
 - Timothy Schacker
 - Sheldon Berkowitz
 - Tom Blissenbach
 - Mike Purtell (Sen Klein designee)
 - KrisAnn Schultz
 - Kerry Hansen
 - Karri LaFond
 - Nicole Brown
- Via phone:
- Lisa Shimmmenti
 - Rae Blaylark
- Members excused:
- Amy Gaviglio
 - Lee Jones
 - Rep. Alice Mann
 - Sen. Scott Jensen
 - Rep. Nick Zerwas
 - Jackie Foster

Approval of minutes

Not applicable, initial meeting

Overview of Council

The meeting was called to order at 4:00pm by Dr. Tolar: Bill is a directive to the Board of Regents to supervise, help the circle of rare diseases. Not a repetition of what others have done in the past. Called for unity, ingenuity, and creativity. Will take into consideration what other states and countries have done, but will approach the problem with novel solutions. Charge to balance idealism with actionable and meaningful actions.

Measure progress against the people we serve. Focus on: 1.) access 2.) cost 3.) patient experience. Progress comes from collective actions.

Review of procedures

Dean Tolar: Knowing this is a directive from the state of Minnesota, will follow the law by:

- meeting regularly, quarterly
- providing an annual report to the state
- following the Robert's Rules (this allows everyone to be heard and avoids one person dominating)
- Determining term limits (not specified in bill-will take feedback from members, Erica Barnes to collect feedback)
- holding open meetings (will be open to the public for attendance but not open to public comment)

New Business

Council member introductions/statement of priorities:

- Finding **common barriers to care** (Erica Barnes)
- Scope of rare diseases in MN (how often do patients come for tx., associated and related costs, disparities). How can we **measure rare diseases in MN**? Paul Orchard
- How can we **connect patients** to best clinical care and also **to research** happening (Dr. Schultz)
- Translational research and being prepared for up and coming therapies. Sees great disparities in care. **Better education to greater MN medical communities** so that families are not traveling to Twin Cities for care (Dr. Beisang)
- How does policy interplay within hospital systems? How can we work in systems to optimize research? How can we **best match patients to appropriate providers**? Can we improve our taxonomy? (Ms Joers)
- How can we transform the system for those that are the sickest? **Virtual care resources such as telemedicine**? How can we build a better system? (Dr. Miller)
- **All** constituents need to **have access** to the health care system (Mike Partell)
- Address the issue of **generations upon generations of things not getting done** in a specific patient community. Address **rural disparities** (Karl Nelson)
- Hoping to get people interested in education and give hope to rare patients and parents. Get the **public involved** (Dr. Beiraghi)
- Establishing **meaningful measurements** will be the difficult part. Should we pick a couple of diseases and ask "did we come up with a plan"? We need to avoid developing measurements that find averages but not to an actual patient (Dr. Mahapatra)
- We **don't have enough research** going on and when we do have a therapy there are too many barriers. Want to see more cooperation among professionals in the system and one way to approach this is to have **care navigators** (Mr. Blissenbach)
- Address barriers, what exactly are the barriers? **"Disability tax" idea to figure out what price a rare patient pays**. Figure out the **disparities**. Find the information that currently exists. **Educate the greater community about the societal costs** (Ms. Ziegler)
- Barriers to care across rare diseases- **identify biggest barriers and address coordination of complex care** (Dr. Berkowitz)
- **Care coordination** is crucial to the rare community (Karri LaFond)
- Understanding the barriers to the rare community (paying for new treatments) rare diseases are on the cutting edge of the new research. **Address rare barriers that will relate to more common diseases**. Resource center? Telemedicine? Can we **gather resources in one place**? Epidemiology alone is crucial (Kerry Hansen)

- Need a better handle on what exactly the barriers are. **What kids are we missing?** More data on knowing **who is being left out of care and why** (Nicole Brown)
- Dr. Shimmmenti was required to step away for patient care, but followed up via email with the following: “I agree, that the greatest barrier is the **access to diagnostics** for moving a patient from undiagnosed to the diagnosis of a rare disease. Right now, we struggle to obtain insurance coverage for whole exome sequencing, and we need to **move access to whole genome sequence or advanced metabolomics analysis**”

Next steps

Dean Tolar reviewed the comments made by the Council, reviewed stated mandate of the bill is to advise on research, delivery, education. Dean Tolar will ask people to make small groups/taskforces (small, single question, then disband). By the next meeting Council will bring information from task forces back to the group.

Dr. Berkowitz requested clarification around what we are charged to do and what is the definition of rare disease? Dean Tolar and Dr. Orchard responded with formal definition (1 in 200,000 prevalence) Raised the urgency of the needs, put defining the problem and solutions on the Council.

Dean Tolar reminded Council to be focused. Important that we remember that the scope is large and we cannot get lost in the vastness of it. We will follow up via email and ask people to be on task forces.

Reviewed procedures of:

- Establish task forces
- Define metrics
- Determine mission and vision
- Report back

Adjournment

Dr. Berkowitz made motion is adjourn at 5:29pm, Dr. Miller seconded motion to adjourn.