

University of Minnesota
Rare Disease Advisory Council

Report to the Minnesota Legislature
2020

University of Minnesota Rare Disease Advisory Council

Report of the Minnesota Legislature

As required by Minnesota Statute 137.68 which went into effect on July 1, 2019.

Submitted by:

Board of Regents

Prepared by:

The report was prepared by staff in the Office of the Dean of the Medical School at the University of Minnesota.

Report Preparation Costs:

Per the requirements set forth in Minnesota Statute 3.197, the cost to prepare this report was \$160.

Background

The Minnesota Rare Disease Advisory Council was established by the State to address the gaps in care for the 1 in 10 Minnesotans living with a rare disease.

The Minnesota Legislature passed a bill for the establishment of a Rare Disease Advisory Council in the 2019 legislative session and requested that the University of Minnesota Board of Regents provide oversight of the Council. The Board of Regents and the Office of President directed the Council be housed in the Medical School under the direction of Jakub Tolar, MD, PhD, Dean of the Medical School and Vice President for Clinical Affairs.

Dr. Tolar chairs the 25 member council and all appointments were filled in September of 2019. The inaugural (quarterly) meeting was held on September 25, 2019. Council appointees represent the following sectors and organizations:

- Mayo Clinic
- M Health/University of Minnesota
- Children's Minnesota
- Various government entities
- Non-profits
- Hennepin County Medical Center
- Gillette Children's
- Private industry
- Payers

Progress during 2019 calendar year

In its first four months, the Minnesota Rare Disease Advisory Council prioritized operationalizing the Council. Progress is as follows:

Council structure

- All members appointed/positions filled for 2 year terms
- Strategic plan drafted (approval from Council pending)
- Work groups established

Building out communications tools

- Initial website design completed
- List of rare disease organizations operating in the state of Minnesota
- Outreach to patient groups initiated to provide a basic introduction to Council

Setting the groundwork for collaboration

- Meetings and communications with National Institutes of Health, National Center for Advancing Translational Sciences held to identify synergies between their priorities and Council initiatives

- Regular communication established with national non-profit organizations that represent the rare disease community with the purpose of engaging in joint activities and receiving support from these organizations (Global Genes, National Organization for Rare Disorders)
- Regular communications established with members from other Rare Disease Advisory Councils across the US

Metrics & outcome measures

The Minnesota Rare Disease Advisory Council subscribes to the axiom “if you cannot measure it you cannot improve it”. Rare disease patient care poses a unique challenge in this regard. The small, widely dispersed patient populations (of which there are over 7,000) have historically not been integrated intentionally in healthcare systems (this is true worldwide) and data on the prevalence of rare diseases, the fiscal impact of rare diseases on the healthcare system, and best practice protocols are scarce. The Council has begun preliminary steps to identify baseline measurement tools for the Minnesota rare disease community. Establishing these baseline measurements will be a priority in 2020.