

## UNIVERSITY OF MINNESOTA

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TO: Chris Steller, Minnesota Legislative Reference Library

FROM: Keeya Steel, University of Minnesota Government and Community Relations

DATE: January 1, 2020

RE: University of Minnesota mandated report: Advisory Council on Rare Diseases

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Enclosed are two copies of the mandated report, University of Minnesota Advisory Council on Rare Diseases Report, pursuant to 2019 Minnesota Laws Chapter 65, Section 1, Subdivision 6.

This report can also be found online: <http://government-relations.umn.edu/state/legislative-materials>

If you have any questions regarding this report or to obtain additional copies, please contact the Government and Community Relations at 612-626-9234.

cc: Senator Paul T. Anderson, Senate Higher Education Finance and Policy Chair  
Senator Greg Clausen, Senate Higher Education Finance and Policy Ranking Minority Member  
Representative Connie Bernardy, House Higher Education Finance and Policy Division Chair  
Representative Bud Nornes, House Higher Education Finance and Policy Division Ranking Minority Member  
Senator Michelle Benson, Senate Health and Human Services Finance and Policy Chair  
Senator John Marty, Senate Health and Human Services Finance and Policy Ranking Minority Member  
Representative Rena Moran, House Health and Human Services Policy Chair  
Representative Debra Kiel, House Health and Human Services Policy Ranking Minority Member

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.