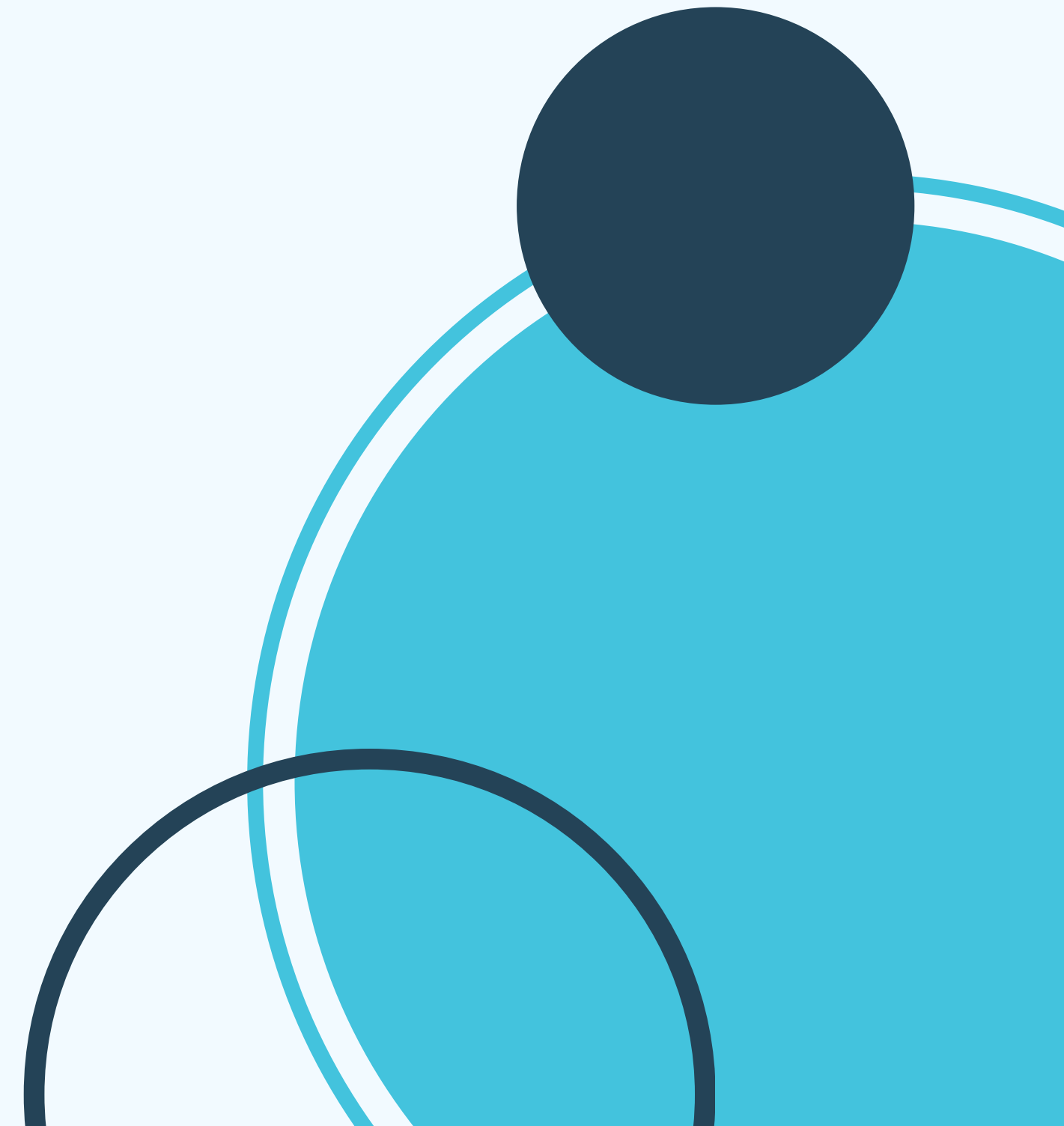


THE MINNESOTA RARE DISEASE  
ADVISORY COUNCIL

# Work Plan 2020



# VISION AND MISSION

## VISION

The Minnesota Rare Disease Advisory Council envisions a state where every Minnesota Citizen living with a rare disease has access to a timely diagnosis, expert/ coordinated care, as well as individualized treatment, management, and support throughout lifespan.

## MISSION

The mission of the Minnesota Rare Disease Advisory Council is to provide advice on research, diagnosis, treatment, and education related to rare diseases.

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# Pillars of Focus

## DEEPEN UNDERSTANDING OF THE NEEDS OF THE RARE COMMUNITY

The Council will acquire a comprehensive understanding of the systemic barriers across patient groups unique to the rare community

## INCREASE ACCESS TO AND COORDINATION OF CARE

The Council will develop recommendations and resources to improve access to and coordination of care for rare disease patients

## IDENTIFY STRATEGIES FOR REDUCING TIME TO DIAGNOSIS

The Council will advise consult and cooperate with multiple institutions in the state to develop information and programs that increase awareness for diagnosis and treatment of rare diseases

## ENCOURAGE THE ACCELERATION OF RESEARCH

The Council will foster the increase of rare disease research through awareness and collaboration



# PILLAR 1: DEEPENED UNDERSTANDING



## WHAT IS OUR ASPIRATION?

The Council will have a deep and comprehensive understanding of the systemic barriers across patient groups unique to the rare community

## WHY IS IT IMPORTANT?

Due to the historic lack of collective consciousness around rare diseases as a class, there are many gaps in knowledge related to rare disease impact and care. For example, the incidence and prevalence of the majority of rare diseases in Minnesota are unknown. Additionally, there is no quantitative information on how many providers with expertise in rare disease care are practicing in the state of Minnesota. These are just two examples. The Council ascribes to the axiom that what you cannot measure you cannot improve.

## CONCRETE GOALS:

- Gather Minnesota specific baseline data on important metrics (i.e. prevalence/incidence, possible population disparities, cost burden of rare diseases)
- Identify most the common barriers to care across rare disease populations in Minnesota across the lifespan
- Directly and regularly communicate with rare patient communities to collect input on additional topics for consideration
- Collaborate with various disease-specific and public health organizations around the country to identify best practices in other states and internationally



# PILLAR 2: INCREASED ACCESS, COORDINATION



## WHAT IS OUR ASPIRATION?

The Council will develop recommendations and resources to improve access to and coordination of care for rare disease patients

## WHY IS IT IMPORTANT?

Among the medical community there are concerns that, for the rare disease population, adult specialists may not exist for a significant group of these patient populations for various reasons. Additionally, the costs of delivery of services/treatments for rare disease patients is a growing concern.

## CONCRETE GOALS:

- Engage the state's medical schools, schools of public health, and hospitals to develop centralized, publicly accessible resources on diagnosis, treatment, and education relating to rare disease
- Identify problems faced by patients when there is a change in health plans and make recommendations on removing these obstacles to finding a new health plan
- Create a list of existing resources on research, diagnosis, treatment, and education for rare diseases
- Apply knowledge from other disease care models (ie more well understood rare disease populations) to improve coordination of care
- Provide healthcare providers with information on best practices so that they are informed of the best strategies for recognizing and treating rare diseases

# PILLAR 3: REDUCED TIME TO DIAGNOSIS



## WHAT IS OUR ASPIRATION?

The Council will advise, consult, and cooperate with multiple institutions in the State to develop information and programs that increase awareness for diagnosis and treatment of rare diseases

## WHY IS IT IMPORTANT?

The average wait time to a diagnosis for a rare disease patient is 6-7 years. Additionally, a rare disease patient is misdiagnosed 2-3 times. This delay in diagnosis creates inefficiencies in the system and significantly negatively impacts the patient's quality of life and health.

## CONCRETE GOALS:

- Provide resources for primary care providers so that they are adequately informed of the most effective strategies for recognizing and treating rare diseases
- Identify current technological tools to assist general practitioners and primary care providers with effective care management of rare disease patients
- Apply advances in technology more comprehensively to the diagnosis of rare diseases (next generation sequencing)
- Advise, consult and cooperate with state agencies to develop information and programs for the public and healthcare community to increase awareness and improve diagnosis and treatment for rare diseases



# PILLAR 4: ACCELERATION OF RESEARCH



## WHAT IS OUR ASPIRATION?

The Council will foster the increase of rare disease research through awareness and collaboration

## WHY IS IT IMPORTANT?

Currently, only roughly 5% of the over 7,000 rare disease patient populations have an FDA approved treatment for their specific disease.

## CONCRETE GOALS:

- Nurture the growth and organizational health of rare patient communities (ie provide basic information to emerging rare communities relative to characteristics of a mature patient community)
- Facilitate connections between researchers and patients, rare disease experts and providers, and among diverse rare disease patient organizations
- Explore approaches to novel clinical trial design