

Ohio Sunset Review Committee Agency Questionnaire

 Agency Name	Rare Disease Advisory Council (RDAC)				
	Lisa Griffin, Director of Government Affairs Ohio Department of Health				
Point of Contact	ct				

Agency's primary purpose and its various goals and objectives

The Rare Disease Advisory Council (RDAC) was created in March 2021 (ORC 103.60). RDAC consists of 31 members appointed by the Governor, the Speaker of the Ohio House of Representatives (2 House, 3 public members), and the President of the Ohio Senate (2 Senate, 3 public members).

The statutory purpose of RDAC is to advise the general assembly regarding research, diagnosis, and treatment efforts related to rare diseases across the state. Rare disease is defined as a disease or condition that affects fewer than 200,000 people living in the United States.

RDAC reports to the General Assembly on:

- (1) The coordination of statewide efforts for studying the incidence of rare diseases in this state;
- (2) The council's findings and recommendations regarding rare disease research and care in this state;
- (3) Efforts to promote collaboration among rare disease organizations, clinicians, academic research institutions, and the general assembly to better understand the incidence of rare diseases in this state.

Agency's past and anticipated workload, number of staff required to complete workload, and total number of staff. The Ohio Department of Health does not have any staff dedicated completely to the Rare Disease Advisory Council (RDAC). ODH is not named in the law as the agency designated for RDAC, but assumed the role when RDAC was created. RDAC utilizes three ODH staff in the Bureau of Child and Family Health for various administrative tasks with scheduling and preparing for meetings. Preparing the report for the General Assembly is an additional task for RDAC.

Agency's past and anticipated budgets and its sources of funding RDAC does not receive any appropriated funds.						

Number of members of its governing board or other governing entity and their compensation, if any
Pursuant to ORC 103.60 (F), the council shall annually select from among its members a chairperson or co-chairpersons. Current chair: Former Representative Randi Clites. There are 31 members total. Members serve without compensation, but may request reimbursement for expenses incurred in carrying out the responsibilities of this Council. To-date, no funds have been expended for reimbursement to RDAC members.

Additional notes							