**Council:**

(iii) receive and consider reports and testimony from expert individuals, the department, community-based organizations, voluntary health organizations, healthcare providers and other public and private organizations recognized as having expertise in rare disease care, to learn about their contributions to rare disease care and possibilities for the improvement of rare disease care in the commonwealth;

**Steering:**

(i) coordinate the performance of the rare disease advisory council's duties with those of other rare disease advisory bodies, community-based organizations and other public and private organizations within the state for the purpose of ensuring greater cooperation regarding the research, diagnosis and treatment of rare diseases. The coordination shall require, when appropriate: (1) disseminating the outcomes of the advisory council's research, identified best practices and policy recommendations; and (2) utilizing common research collection and dissemination procedures;

(f) On or before December 31st of each calendar year, the advisory council shall file a report with the clerks of the house of representatives and the senate and the executive office for administration and finance, which shall include, but is not limited to: (i) a summary of the current state of comprehensive rare disease plan for the commonwealth; (ii) those actions taken and progress made toward achieving implementation of the comprehensive rare disease plan; (iii) an accounting of all funds received by the council, and the source of those funds; (iv) an accounting of all funds expended by the council; and (v) to the extent practicable, an estimate of any cost savings on the part of individuals and the commonwealth that will occur upon full implementation of the comprehensive rare disease plan and accompanying programs.

SECTION 3. On or before 180 days following the effective date of this act, the rare disease advisory council shall provide a preliminary report to the governor, the department of public health and to the general court, by filing the same with the clerks of the house of representatives and the senate. The preliminary report shall include, but is not limited to, an estimate the financial, informational and other resources needed to achieve the goals and duties of the advisory council.

**Research:**

(ii) using existing publicly available records and information, undertake a statistical and qualitative examination of the prevalence and causes of rare disease to develop a profile of the social and economic burden of rare disease in the commonwealth;

(vii) research and determine the most appropriate method for the commonwealth to collect rare disease data, including a database of all rare diseases identified in the commonwealth along with known best practices for care of said diseases and such additional information concerning these cases as the advisory committee deems necessary and appropriate to conduct thorough and complete epidemiological surveys of rare diseases, subject to all applicable privacy laws and protections;

(v) determine the human impact and economic implications of early treatment of rare diseases versus delayed or inappropriate treatment of rare disease as it pertains to the quality of care, the quality of patients’ and their families’ lives, and the economic burdens; including insurance reimbursements, rehabilitation, hospitalization and related services on patients, families and the commonwealth;

(vi) evaluate the current system of rare disease treatment and available public resources to develop recommendations to increase rare disease survival rates, improve quality of life and prevent and control risks of co-morbidities for rare disease, based on available scientific evidence;

**Advocacy:**

(iv) develop methods to publicize the profile of the social and economic burden of rare disease in the commonwealth to ensure that the public and healthcare providers are sufficiently informed of the most effective strategies for recognizing and treating rare disease;

(viii) examine the feasibility of developing a rare disease information and patient support network in the commonwealth to aid in determining any genetic or environmental contributors to rare diseases; and

(ix) develop and maintain a comprehensive rare disease plan for the commonwealth, utilizing any information and materials received or developed by the advisory council pursuant to this subsection, and which shall include information specifically directed toward the general public, state and local officials, state agencies, private organizations and associations, and businesses and industries.

**Fundraising:**

(e) The advisory council may apply for, and accept, any grants of money from the federal government, private foundations, or any other source which may be available for programs related to rare diseases or to advance the mission of the advisory council.